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PHYSICIAN - JEWISH FAMILY COMMUNICATION ABOUT FUTILE MEDICAL TREATMENT: A QUALITATIVE APPROACH

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A Thesis

in

The Department

of

Religion

Presented in Partial Fulfilment of the Requirements
for the Degree of Doctor of Philosophy at
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ABSTRACT

Physician - Jewish Family Communication About Futile Medical Treatment: A Qualitative Approach

Myer Schecter, Ph.D.
Concordia University, 2001

The purpose of my research is to see how hospital physicians and Jewish families perceive their communication when further aggressive treatment of the patient is considered futile. Today's hospital physician has little time to get to know the patient and finds it easier to communicate with the family, especially in the medically futile situation. Other forces impinging on communication include the high cost of hospitalization, which pressures physicians to release patients as soon as possible, and a short-staffed medical team. The family's desire to prolong life is often based on their religious beliefs and culture or their internal values, feelings and traits which emphasize prolonging life. In my research, I interviewed physicians, families, nurses, administrators and families in cases of expressed difficulties in communication disagreements about futility. I found that families and physicians were at odds in their understanding of futility and their perception of how they communicated with each other. My last chapter offers a collaborative model of good communication and suggestions of how to deal with the pressures on families and physicians in these most difficult times.

ACKNOWLEDGEMENTS

The Halacha (Jewish Law) says that we are obligated to give thanks for favours received. Although I'm committed to the Halacha, I'm offering these few words not because of it but in a spirit of gratefulness which comes from within. I have many people to thank. I enjoyed writing this thesis. I felt it was important. It is a subject I live with at the Jewish General Hospital (JGH). The people who assisted me were very caring and cooperative. They reached out to me.

I thank the physicians, nurses, administrators and families who I interviewed. They gave not only of their time, but an insight to the subject matter. It was an education.

I thank my mentors and advisors, Dr. Frederick Bird, professor and former Director of the Ph.D. Program, Department of Religion at Concordia University and Dr. John Williams, Director of the Department of Ethics and Legal Affairs, Canadian Medical Association. They were always, always available. They are not only scholars - ethics becomes alive in their presence.

I thank Ms. Gigi Grein, my typist and computer expert who has been with me throughout this research. She has never failed me in producing the many drafts, always on time. It was a comfort to have her reliability and loyalty.

I also owe a debt of gratitude to Dr. Jean Paul Collet, Director of the Randomized Clinical Trial Unit at the JGH and Associate Director of Clinical Research at the Lady Davis Institute of Research; and to Dr. David Langleben, Chief of the Division of Cardiology at the JGH for their invaluable input, especially as I began the research.

To my dear wife, Miriam, Bereavement Officer at the JGH who contributed many ideas and always encouraged me to continue my studies.

Finally, and most importantly, I give thanks to Hashem, the Good Lord who has given me the fortitude, good health and wisdom to complete this thesis.

Rabbi Tarfon said:

You are not obligated to complete the work; but neither are you free to desist from it.

Talmud, Pirke Aboth 2:21

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INTRODUCTION AND METHODOLOGY

This project germinated towards the end of the 1980s as a research proposal for my doctoral thesis at Concordia University's Department of Religion in Montreal. As Director of Chaplaincy Services at the Sir Mortimer B. Davis Jewish General Hospital, a hospital of approximately 650 beds, the main part of my duties included visitations with patients and families, most often dealing with their expressed spiritual and psychosocial needs. The most difficult part for me was working with terminally ill patients and their families. There were also issues of medical futility when physicians declared further treatment of a patient as hopeless and inappropriate. This is a phenomenon often discussed in the literature and it was especially magnified in the 1990s because of government financial restraints and pressures to have the patient released from hospital as soon as possible or to be transferred to a palliative care unit. But other changes were rapidly taking place.

I was beginning to notice a serious erosion in the physician/patient relationship, something always considered sacred. Physicians hardly knew their patients. Their offices, in and out of the hospital, were filled with patients whom they could see for only a few brief moments. Physicians only knew their patients from their charts which contained medical facts, nothing personal. They were losing sight of the people behind these charts, their feelings, history and life goals. Within the hospital, the disintegration

of the physician-patient relationship seemed more problematic. Patients were coming into the hospital and released at a very rapid pace. Government shifts towards day surgery and home care became important factors. Even patients needing a hospital stay were briefly seen by many specialists who really didn't know anything about the patient's personal life. I also noted a strong trend towards more family involvement. Physicians would turn to the family for help in communicating and decision making, especially in cases of terminally ill patients. Physicians did not have the time to spend with their patients as in the past. Thus, the pressure of government cuts and health care reforms seriously affected patient care including the traditional sacred doctor/patient covenant.

Further to these changes was the mercurial pace of medical technology and medicine which was not only prolonging life but prolonging death. The average patient age in our hospital jumped from seventy to seventy-eight years within a fifteen year span. As the average patient age rose, families became more involved. Physicians now relied on the family and decisions were made together with the family. William May described these decisions as part of quandary and virtue ethics.[1] Physicians, patients and families had the quandary decisions about how to treat the patient medically, but once the decision was made, a new set of ethical issues came into place. What do we do with the patient when released? Who will take care of the patient? This usually fell to the family. In terminally ill cases, family involvement was accentuated. In addition, it is not easy to speak directly to the patient about his/her illness. It is easier to speak to the family. In fact, from my experience and research, most physicians and surgeons have to deal with families who are anxious to hear how the patient is faring while the terminally ill patient

is not ready to hear "the whole story". The patient's major concerns are discomfort and uncertainty whether the doctor will be there when needed.

Third, the older traditional approach of physician paternalism began to erode. With advances in the ethics of autonomy, physicians began to feel uncomfortable without consulting and involving the patient and family. Informed consent became standard practice. Legal and ethical issues also came to the fore. Nursing and administration began to ask questions, even challenging the physicians in their approach to medical care. I would hear complaints, "Rabbi, it's not the same as it used to be - even the nurses give you a hard time." This process of change was fast. The extremely busy physician hardly had the opportunity to step back and analyze what was happening.

Finally, the rapid increase of Internet patients has become a new phenomenon. Patients can now click onto the worldwide web, accessing medical journals, news services, patient education hand-outs, clinical practice guidelines, drug databases, discussion forums, continuing education classes and interactive forums. The *Montreal Gazette* reported, "It's a reality of a new millennium type of medical practice." Ms. Trudy Novack, a patient of the Jewish General Hospital diagnosed with ovarian cancer, candidly says, "If you feel your doctor is not on top of things, you can be on top instead. It makes you feel you have more control... There is a problem with doctors being so busy... My doctor has such a heavy patient load, I don't know how he could possibly have the time - unless he is a speed reader - to know everything that is going on."[2]

In one of my courses with Dr. John Williams, we found ourselves struggling with the different models in physician/patient relationships. It was during this course that it

dawned upon me to write about the physician/family relationship which I felt was a newer medical concern. I spoke further to Dr. Fred Bird, my thesis advisor, and we began working on it together. If I would concentrate on physician/family communication about medical futility, which is an extremely important ethical issue, I could also find information on how both feel about medical futility and the roles of the physician and family. I would, perhaps, get a newer perspective on the dynamics of medical futility and their impact upon physicians and families. Further, after analyzing the perceptions of physicians and families in the medical futile situation, I might garner a better insight on how to communicate under these stressful situations.

As I set up a research protocol, I stayed with Dr. Frederick Bird, Director of the Department of Religion at Concordia, and Dr. John Williams, Director of the Department of Ethics and Legal Affairs, Canadian Medical Association as my advisors throughout the project.

The Literature

The literature on family/physician relationships in communication is sparse. I did find one book titled, The Patient and the Family[3] and one whole issue of the *Journal of Clinical Ethics* in the Fall of 1991, Volume 2, Number 3. There are some articles which I quote in Chapter V titled, "The Family Setting", but the literature may be summarized as Nelson and Nelson write in the Encyclopedia of Bioethics in the entry title, "Family":

> By and large, bioethics has little to say about the moral significance of the family within the context of medicine. The explicit

> discussion of the family in the third edition of Tom Beauchamp's and James Childress's Principles of Biomedical Ethics is confined to one paragraph stating that the burden on the family must not be determinative in decisions to refuse treatment (Beauchamp and Childress, 1989). The U.S. President's Commission for the Study of Ethical Medicine and Behaviourial Research devotes no more than ten lines in a text of 545 pages of Deciding to Forego Life-Sustaining Treatment to the family's role in medical decision-making at the end of life (U.S. President's Commission, 1983). The Hastings Center's Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying mentions families only in passing in the role of surrogate decision-makers or people who have feelings for the patient. (Hastings Center, 1987) Alan E. Buchanan and Dan W. Brock's Deciding for Others views families as aggregates of competing individual interest and devotes much of its brief discussion of the family to the possibility of selfishness and disagreement among family members (Buchanan and Brock, 1989). We note also that the first edition of this encyclopedia contained no "family" entry.[4]

In my view, this mistrust of family is symbolic of the hospital's traditional fear of the family as Nelson and Nelson point out above in their encyclopedic entry.

Methodology

In this study, I used a qualitative approach. The study was designed primarily to get an insight into communication between doctors and families in terminally ill cases which engendered conflict. As I will explain, I estimate only about 5% of our patients and families have this type of conflict with the physician. Most families agree with the medical decisions to terminate all aggressive treatment. The qualitative approach has an inherent weakness for the doctors while it has strengths for families. Physicians are scientific. They seek the hard facts. They are distrustful of any attempt to measure communication, comments on feelings, opinions, emotions, personal reactions, attitudes

and personal judgements which they refer to as anecdotal reports and perceptions. Families see it differently. For them, the qualitative approach gets at the qualitative issues about what is happening to the family and physicians and the communication between them. While qualitative issues are hard to measure, they are real, a fact of life. Further quantitative studies could be undertaken by dissecting my conclusions and finding a quantitative approach which would prove or disprove my hypotheses on these issues.

In setting up my research, I struggled with complicated methodologies which would have paired and joined each physician and family into a case-study. Both families and physicians balked at the idea because of issues in confidentiality. Dr. Bird suggested a simplified approach which would guarantee complete confidentiality. I would not pair physicians with families but speak to each separately without mentioning names. I would approach the physician and ask, "Can you explain your approach to families of terminally ill patients? How do you tell the news to the family? Do you have a specific style? Should families have a right to decide in medical situations? How do you communicate with an intransigent family which insists on aggressive treatment in the futile situation?"

To the families I would ask in general terms, "Can you tell me of your experience? Tell me the whole story. I do not want the names of your doctors, but how was the news broken to you? Did the doctor speak to you first or to the patient? Did they give you enough time? What do you feel about the rights of families in your situation? Do you feel comfortable talking to the doctors or are you afraid of antagonizing someone? In an intransigent situation, when doctors and families disagree on terminating life in a futile situation, who should have the final say, doctors or the

family?" At Dr. Bird's suggestion, the floodgates opened. Doctors were more than happy to participate. Families, too, were anxious to tell their story. The fears and concerns dissipated. We were on neutral grounds where everybody could now feel at ease.

Strengths and Weaknesses of this Approach

At the suggestion of Dr. Bird, I interviewed physicians and families under no pressure. Physicians told me about their style in communication, their concepts of futility and their roles and rights in the medical futile situation. They took a global view, not tied to any one patient, but based on their overall experience. They explained and complained about the changes in health care. I got a fairly good view of what they described as futility, how they handled it for themselves, for the patient and family and what they considered ideal communication.

From the family I got the narrative - their story of what happened in the case. I began to see differences in what doctors claimed to be good communication and what families perceived as good communication. With the cross-section of families interviewed, I saw how they perceived terminal illness and futility when their loved ones were involved. They, too, explained and complained about the health care system. The bottom line was that families have rights and obligations to their loved ones which the physicians cannot abrogate at will.

The first drawback was that I, a hospital chaplain, was the interviewer. People

may have tried to impress me and may have not honestly expressed their feelings. They may also have been wary of my questions, since I am paid by the hospital. It is possible that some may have held back on telling the whole story, especially when my interviews were in-hospital while the patients were still under hospital care. On the other hand, my social work and business background[5] made it easier for me to connect and cement relationships. I could touch and hug patients and families with comparative ease. Relationships were thus bonded. They also had my promise of confidentiality and, in many cases, I was first contacted by the families and doctors.

Second, I have a religious bias towards Orthodox Judaism, and although I try not to impose or express any of these religious values to the physicians or families, it may be certain that they play a role in the decision process. I would like to think that this is a strength rather than a weakness. I personally believe that anyone involved in ethics, and especially ethicists, are better with religious backgrounds. I realize that this may be hotly debated, but I have concerns about ethicists who tend to avoid certain terms of morality as an anchor to their principles. With their reasoning, you could fall into a trap of an extreme form of situational ethics where everything could be rationalized as ethical. I think that my religious background has been an asset to my approach towards physicians, patients and families and they appreciate it. I also wish to emphasize that this thesis had nothing to do with pastoral care - which is a completely different subject. Pastoral care involves a spiritual assessment where rabbis try to assess what is important to the patient. It is not what the pastor believes. It is what the patient and families believe. In contrast, although some of my cases involved religious issues, most of them

have nothing to do with religious matters. The patient and family are usually not religious although culturally commited to Jewish practice. They are interested primarily in the physical care of the patient. It is normal and accepted in our hospital that the families call the rabbi to intervene for purposes of care. "After all, Rabbi, this is a Jewish hospital. What about the care we are getting?"[6]

Third, I admit to a bias towards the family and their concerns in our hospital setting. As will be shown, the role of families, their ability to communicate and answer to the physician is diminished in the hospital - the traditional turf that belongs to the medical professional. The hospital is strange and frightening to patients and families. Any sense of control is taken away from them. They become lost, overwhelmed and angry. My feeling is that someone has to try and help. Again, this does not mean that I have abandoned the physician or their interests. I know of their pressures, concerns, and political changes which have taken place and their loss of control. I know of the families that are unreasonable, difficult, always complaining, hot-tempered, and of the physician's composure. Almost all of the physicians are caring. It is just that the nature of the hospital setting gives them the power over the family.

Finally, there is a strength in my fluency in Yiddish. Many of our Jewish patients are older with European backgrounds, some Holocaust survivors. They feel comfortable in Yiddish. I could relate to their past; many of them came from religious or rabbinical families. Some would ask me the question, "Farvahs Rebbe farvahs? A million un a halb kinder!" [Why, Rabbi, why? A million and a half children! (died in the Holocaust)] They knew I had no answer but a bond was formed. They could

express themselves to a rabbi and in their own mother tongue. We could talk freely.

Interviews and Hypotheses

My interviews included 23 physicians, 28 families, 6 nurses, 4 residents, 6 students, and 2 from administration. There was no specific reason for this number, except that I wanted to get a cross-section of physicians from the various medical units and the team in general. The physicians came from the departments of Oncology, Surgery, Internal Medicine, Palliative Care, Infectious Disease, Cardiology, Pulmonary, Intensive Care, Obstetrics, Family Medicine and Geriatrics. There was one doctor who was in research, a former pediatrician. Many were heads of their respective departments and all were known as good communicators.

For my family interviews, I chose to interview those who had expressed problems in communication with physicians. Most of these interviews were in-hospital. Some were from a random selection. I would go to synagogue and, immediately after services, explain my research asking if anyone who was saying the *Kaddish*[7] would mind telling me their story. I would then make an appointment to meet them at their home. Others I would pick up at Shiva homes where it was quite common to hear what happened to the family and patient at the end of life. I would listen to their stories and then interview the families privately.

My questions were narrowed to the following for the physicians:

1. How and when did you tell a family bad news?

2. Do you have a specific style or approach in explaining the bad news to the family?
3. How do you feel about families who wish to prolong the life of a family member in futile situations? Do families have a right to interfere or does only the patient have the right?
4. What do you do in an intransigent situation where families have insisted on prolonging life which you thought was futile?

For the families I asked:

1. Tell me your story. What exactly did the doctor tell you, as you recall, of the futility of the situation?
2. Was it a one-way or a two-way conversation? Did he/she encourage you to ask questions?
3. Do you feel that families have rights in making decisions in futile situations?
4. Do you feel that doctors can make the final decisions on stopping all treatments or does the family have the last say?

Of course, we followed the physicians' and families' lead as in any qualitative study. We let them set the agenda about what they wanted to talk about but we endeavoured to make sure that we had answers to these four questions. The answers, in most cases, were taped. Some physicians and families were reluctant to tape, so I took notes.

The major hypothesis of my study is based upon Dr. Bird's model of Good

Communication. In one of his essays, Bird spells it out.

> Merely stating normative standards is not an example of ethics, because ethics involves not merely the articulation of standards of behaviour but an act of communicating that seeks to persuade by setting forth justifying reasons. Nor can ethics simply be equated with customary or conventional conduct. Such conduct may be moral. In contrast, ethics refers not to the behaviour itself but to the communicative activity insofar as it affected how those involved decided to act.[8]

In other words, Bird is trying to put wheels on ethics. On its own, ethics is usually something discussed over a cup of coffee, concerning which standard of behaviour is ethical or not. With his model of Good Conversation, Bird gives ethics a chance to move, produce and influence the decisions people make about how they ought to act. Bird argues that Good Conversation is ethics in practice wherein people do not have to remain morally blind, deaf or mute, but can create a social activity which can help people overcome their sensory incapacitations and establish and maintain agreement among themselves.

In following Bird's lead, my major hypothesis is that "good communication will lead to resolving physician-family conflict in the medically futile situation". This collaborative model in communication I describe in Chapter VII of this thesis. The other chapters describe primarily the setting of the medically futile milieu, environment, the stakeholders and their problems. I will note how families and physicians perceive futility, their concepts and knowledge of ethics and their understanding of each other's position. I will look at the different models for resolving the issues in medical futility, the pressures within government and the role of the physicians and duties of families in this most difficult situation. I will also note the different psychosocial attitudes of Jewish

families, especially as they are expressed in this most difficult time. It is my belief that all these issues impinge upon the nature of communication between physicians and families and thus, it is very important that we study them and see how they can be resolved through Bird's Good Conversation.

There are secondary hypotheses which will be expressed throughout the thesis. These will be noted from the psychosocial attitudes of physicians and families from their setting and the interviews. All of these will lead to a better understanding in the final chapter and the model and suggestions therein.

Definitions

For the purposes of this study I have adopted the following working definitions of the key terms used in this dissertation.

1. Communication: The exchange of information between the physicians, families and patients. It deals mostly with information having to do with medical futility when families, physicians and patients are confronted with the ethical issues about treating patients, who by physicians' accounts, are considered too ill to be treated aggressively. Thus, communication becomes a moral interaction as Bird explains, "By means of communicative moral interactions, humans seek to establish and gain compliance with social agreements that set forth standards of how people are expected to behave. We engage moral communication whenever we are trying to persuade others to consent to such conduct-shaping agreements by intelligible

arguments."[9] It is perhaps this moral element which explains why communications are often misunderstood and divisive.

2. Physician: The physician in my research refers primarily to the doctors considered geographic full-time in the hospital (GFT). It also includes medical residents involved in their required residency, fellowships, etc. Some of the physicians and surgeons maintain offices outside the hospital, but their work outside office hours is on hospital premises. The research did not involve physicians whose major practice is outside the hospital.

3. Family: This is the immediate family of the patient or closest relative or friend when there is no immediate family. Usually the families will have spokespersons chosen from within to be the major communicators on their behalf. The term, "Jewish" families, refers to families of Jewish origin no matter what their religious affiliation (Orthodox, Conservative, Reconstructionist, or Reform). Non-religious, cultural, or social affiliations are also included.

4. Patient: It refers primarily to the patient in-hospital. Occasionally it will include out-patients who visit the clinics. I do not include the patient who only visits his/her doctor in their outside offices.

5. Futility: Futility is the term used by physicians when they decide that further treatment is medically inappropriate because there is no chance for the patient to improve their situation. Futility most often includes value judgements. Doctors and families may have different conceptions of what is futile.

It is popularly estimated that only about 5% of our patients and families will

differ with their doctors on their conceptions of futility. The vast majority will accept the doctor's opinion. This does not mean that the patient or family is completely satisfied with the communication or even the general treatment of the patient. It only suggests that the family is in accordance with the physician that further treatment should be suspended on the grounds of futility.

6. Religious families: This term appears fairly often in regard to efforts to resolve the conceptual differences in medical futility. Religious families may point to theological objections to accepting the doctor's opinions. For my purposes, religious families include those who are Sabbath observant and regularly attend synagogue. Of course there are secular Jews who also disagree with the physicians on the futility issue. I do not wish to define who is or is not a religious person or what religion is in general.

7. The Montreal Jewish Community: A few pertinent remarks must be said about the Jewish community since the Jewish General Hospital is considered the "crown jewel" of the community. The community is unique in that the vast majority of its synagogues are Orthodox. It has over fifty Orthodox synagogues, five Conservative, one Reconstructionist, and one Reform.[10] All three funeral homes do their various services according to Orthodox practice. For my purposes, while most Jewish Montrealers are not Orthodox in their personal practice, there is a great respect for Orthodoxy at the end of life. This spills over to burial practices and a general disdain for autopsies and cremation. In other cities you may find different statistics and attitudes.

8. The Sir Mortimer B. Davis Jewish General Hospital: Our hospital, known as "The Jewish", was built in 1933 to accommodate Jewish patients who were having difficulties adjusting to their stays in the non-Kosher hospital system. There were also Jewish physicians who, in those years, could not find a hospital which would accept their membership, since all hospitals were privately operated. Thus, our hospital is, even over 65 years later, strictly Kosher. All restaurants and secondary non-medical activities are suspended on the Sabbath and Jewish holidays in accordance with Jewish religious practices. We have approximately 250 Jewish patients in a total of 650 beds, including the long-term care, amounting to about 37% of the hospital population. We have daily and holiday religious Hebrew services. The ambiance of the hospital has remained Jewish in accordance with the wishes of the larger Jewish community. Thus there are outside pressures to follow traditional patterns in end of life issues.

Outline of the Dissertation

Chapter I introduces the futility debate and what it means for physicians and families. It then offers an historical background to the concept of futility, the traditional medical paternalistic attitudes and the rise of patient autonomy. It discusses Jewish and Christian beliefs in the framework of physician rights versus patient autonomy and some of the current approaches in the various codes of medical ethics.

Chapter II focuses on the concept of futility and the four major models which

address the futility issues as seen through the eyes of eight physicians and ethicists. I will offer my critique of these approaches and begin to introduce my collaborative model in communication.

Chapter III gives a grasp of the physicians' setting in the debate. I examine the student and resident physician training in medical ethics and how the modern physician must cope within government and hospital administration.

Chapter IV re-examines and further explores the futility debate through the eyes of the physician. I then turn to the physician interviews, evaluate their responses and attempt a critique based upon the literature and personal experience.

Chapter V discusses the pros and cons of family involvement in the futility decision process. I also look at Jewish family values and psycho-social traits which may affect coping with the life-threatening illness. Finally, I examine the Jewish family in the Montreal Jewish community and especially in the context of the Jewish General Hospital.

Chapter VI deals with the family interviews, their perception of futility and physician-family communication. I will also show how Jewish family values and traits are demonstrated within the interviews. Finally, I will assess and evaluate the findings.

Chapter VII is the crux of my research. Here I examine the specific areas and problems families and physicians have in communication in the medically futile situation. I concentrate on why and when these problems arise and what can be done to solve them. Using Fred Bird's model of Good Communication, I propose a collaborative model which all the parties involved in the debate may find useful.

Notes

1. William F. May, The Patient's Ordeal (Bloomington: Indiana University Press, 1991), 13.

2. Jeff Heinrich, *Montreal Gazette*, 24 December 1999, B-1.

3. Hilde Lindemann Nelson and James Lindemann Nelson, The Patient and the Family (New York: Routledge Press, 1995).

4. Hilde Lindemann Nelson, James Lindemann Nelson, "Family", Encyclopedia of Bioethics (New York: Simon and Shuster, McMillan, 1995) vol. 2, 801-807.

5. As a social worker, I worked at John Howard Society for three years in St. Vincent-de-Paul Penitentiary from 1967-1969. I also worked for my father's menswear clothing company for many years. Rabbinical duties and business are not incongruent. In fact, they go hand-in-hand according to the tradition. In the Talmud we read, "Do not make the Torah as a tool in which to dig." In other words, don't use Torah scholarship to earn a living. Many of our Talmudic sages and especially Maimonides eschews earning money from the rabbinate. To this day there are thousands of graduate rabbis in business, in the professions and in universities and some are especially connected to medical ethics such as Drs. M. Tendler, J.D. Bleich, A. Steinberg, F. Rosner, A.S. Abraham and Rabbis I. Jakokovitz, M. Feinstein, E. Waldenburg, D. Feldman, L. Meier and I. Breitowitz.

6. The Sephardic Jewish patients may have a different view of their rabbi who is there primarily for ritual purposes and in end of life religious observances.

7. *Kaddish* is a special prayer said by family mourners for eleven months in synagogue after death of the family member.

8. Frederick B. Bird, "The Role of Good Conversation in Business Ethics", Boston College Ethics Initiative Committee, The Wallace E. Carroll School of Management, Boston College, Chestnut Hill, Massachussetts, 1991, p. 15.

9. Frederick B. Bird, The Muted Conscience: Moral Silence and the Practice of Ethics in Business (Westport, Conn.: Quorum Books, 1996), 196.

10. National Synagogue Directory 5760/1999-2000. Canadian Jewish Congress, Montreal, Quebec. 5760/1999-2000. There are a number of synagogues of Hasidic origin which are not registered with the Congress.

CHAPTER I

FUTILITY: THE HISTORICAL AND RELIGIOUS CONTEXT

Futility, in the medical context, bears a stamp of finality. It can be a harsh, powerful term as it confronts families of dying patients. It may conjure many conflicting feelings among family members. Some may feel resigned or relieved; others may want to try more aggressive and experimental treatment in order to save a loved family member. Still others may have mixed feelings which leave doubt, whether from feelings of denial, guilt or anger which engender a desire to prolong life or end suffering.

Every day, issues involving futility arise in hospital settings. These include life and death decisions. We philosophize about quality of life, the rights of patients, families, and physicians, the sanctity of life, the duties of physicians and the opposing duties of families and exactly where society should put its halt on the "slippery slope". We, also, may debate definitions of futility in the context of a hospital as opposed to those of a loving family. Finally, religious beliefs and practices surrounding end of life issues may ultimately prevail for some in the end.

There are other problems in the futile medical situation. Sometimes it is the lack of comprehension on the part of the family about what the physician is saying. It can be a concept which is vague and unclear. For example, PVS (permanent vegetative state) is a condition in which the patient is cut off from normal patterns of communication. In

such an event, ethical controversy and confusion is engendered by ambiguous terminology. This can be confusing to the family. One issue is whether artificial nutrition and hydration is an optional medical treatment or whether it is considered obligatory care for all patients. CPR (cardiac pulmonary resuscitation) is often an exercise in futility. When the family of a geriatric patient is informed that there is a 1 in 10 chance that it may benefit the patient, there is confusion. In this case, the physician may consider it a futile procedure. Thus, the ambiguity in defining futility arises from linguistic errors, differences in understanding statistical information, and disagreements about the goals of therapy. Our research will show that there are often unexpressed feelings in those involved in the decision process. Because of these misunderstandings and emotional unexpressed aspects of family responses as opposed to the scientific approach of the physician, communication is often difficult. The families and physicians appear to be on different wave lengths not realizing that they are speaking past each other, not towards each other. Indeed, it is a delicate balance and we tread on "holy" ground involving life and death. Usually there is sensitivity and those involved will seek a common approach on how to proceed in treatment.

The common major argument in support of futility as a criterion for foregoing life-support, even without informed consent of patient and family is usually expressed as follows:

> We physicians have lost much control of our daily activities and destinies because of managed care, utilization review, etc. Now patients, or their frightened, guilt-ridden, death-denying families seem to think they can force us to perform CPR until *rigor mortis* occurs because physicians must obtain informed consent before they can discontinue maximal intervention. The line must be drawn somewhere and we must, at the

> very least, retain control over our own behaviour. Patients may have the right to refuse certain procedures, but have no right to receive whatever they want. Just as it is inappropriate to discuss laetrile (a material claimed by unorthodox practitioners to be effective in treating many types of cancers) as an option in cancer therapy, so it's inappropriate to discuss CPR when it's futile. Prescribing futile interventions breaks trust with patients, exploits fear of death, feeds inflated ideas about what medicine can achieve, enhances for the patient not autonomy but the illusion of autonomy, enforces physicians to neglect their real duties in helping dying patients.[1]

Those who oppose the above argument and insist upon patient autonomy and informed consent before any decision is made could argue from the following analogous situation:

> How would you feel if one morning you brought your car to a shop for repair and when you came back for it in the evening, the mechanic said he had dismantled and sent it to the junkyard because he had made a *mechanical* decision that it was futile to repair the car, and therefore your informed consent was irrelevant?
>
> What if the mechanic said that he was a graduate of the University of Southern California School of Auto Repair, was licensed and very experienced, was the President of the American College of Auto Repair, and knew more about cars than you ever could? What if he informed you that as a matter of fact, the problems of your car met the criteria of futility as defined by the consensus reports of the AMA (American Mechanical Association), the SCCCM (Society of Critical Car Care Mechanics), and the County Network of Mechanical-Ethics Committees? Would that make his behaviour more acceptable?
>
> What if, instead, the mechanic phoned you in the afternoon and told you that he was about to sign an order to dismantle and load your car onto a junk truck and that the cost involved would have to be borne by you and/or your insurance company, and that he was simply disclosing this to you out of courtesy? Wouldn't that be acceptable?[2]

In order to illustrate the above two major forces which impinge on futility, let us take a typical example of this argument faced in an ICU (intensive care unit) of an average Canadian hospital.

Our patient is an 80 year-old Jewish lady married with one daughter who worked

for many years as a cleaning lady for various families in the Jewish community. She had a history of bronchitis with a few incidents of bronchial pneumonia. In recent years she had more and more difficulties in breathing and had to be admitted to the hospital on several occasions. On this occasion, her condition seemed very bad and she was admitted to the ICU and intubated. Her condition worsened. She became febrile, disoriented and unresponsive. All attempts to wean her from the respirator had failed. The doctors and nurses saw the case as hopeless and approached the husband to agree to an order gradually reducing the level of intubated care in order to see if she could eventually make it on her own or allow her to die peacefully. It was judged futile to keep her on ventilation when there was estimation of no possibility of cure, or any meaningful quality of life in the future. The husband and daughter refused the suggestion. They first asked about her chances of survival without the intubation and explained that it was her will as a former Holocaust survivor that she be treated aggressively right until the end. She was a fighter.

Futility in a Head-On Collision

The family's position placed the ICU physicians in a difficult position. The family and the ICU team were incompatible. They separately gathered forces to support their views. The physicians called upon the Ethics Committee to intervene while the family approached their rabbi and lawyer, indicating they were going to put up a battle. We examine their arguments. The physician would say, "I have an obligation to heal

and prevent suffering. To this I am committed. When the medical situation is futile, and cure is not possible, the patient is to be allowed to die or referred to palliative care. In either case, the family is sensitively informed of the situation. The family, however, has no right to impose their personal wishes on my professional obligations as a doctor."

On the other hand, the family would say, "We have an obligation to do everything in order to save our family member. To this we are committed. Even if the medical situation is deemed futile by the experts, it is our duty to make sure that our family member is treated until the end, as the patient expressed before he/she passed away. We do not agree to cease any further treatment or have her entered into a palliative care unit. In all events, we want to be part of the decision process. The physicians have no right to impose their professional wishes upon our personal obligations to our family member."

This argument between physician and family contain the key words which we are discussing in our thesis. They are futility, Jewish family, physician, rights and duties, and communication. This chapter will deal with futility.

The Historical Background to the Futility Debate

The conflict between these often opposing principles of paternalism[3] and autonomy can be readily observed in the history and evolution of the principles of medical ethics and codes. The Hippocratic Oath (500 to 400 BCE) has always been referred to as the founding code of paternalistic medicine. A major theme was that the physician was there to benefit the patient "according to my ability and judgement".

Further, it was the duty of the physician to protect the patient from mischief and injustice which may be inflicted upon him/herself if the "diet is not properly chosen"[4]. We also read in the section called **Decorum**, "give necessary orders with cheerfulness and serenity turning his attention away from what is being done to him... revealing nothing of the patient's future or present condition. For many patients to this cause have taken a turn for the worse".[5]

Maimonides, the physician, philosopher, and codist of the twelfth century, is also paternalistic in his approach. In his "Daily Prayer of the Physician" we read,

> Grant that my patients have confidence in me and my art and follow my directions and my counsel. Remove from their midst all charlatans and hosts of efficacious relations and know-all nurses who arrogantly frustrate the wisest purpose of our art and often lead thy creatures to their death.[6]

But even within the framework of the Hippocratic writings and prayer of Maimonides, we detect signs of autonomy. In the **Decorum** we read the expression, "give encouragement to the patient to allow himself to be treated", a statement that shows concern for the will of the patient. Within Maimonides, too, we read into the initial portion of the prayer that the patient should have confidence in the physician as if to say, it is ultimately up to the patient. Further, both treatises also show concern for the psychosocial well-being of the patient and this, too, is inherently part of autonomy. While the physician's basic approach is authoritarian, attitudes and concern for the patient's acquiescence to be treated are always at hand. The psychological dimension of the patient's desire to get well was recognized as an important part of the healing process. Throughout the following centuries and especially after the Renaissance, the

conflict of medical authoritarianism versus the patient autonomy grew stronger. As science progressed, the art of medicine changed drastically. In previous years, from the time of the Hippocratic Corpus, medicine was holistic in nature. The belief was that the purpose of medicine was to assist human nature in restoring the individual's physical destruction from its natural order. In the Hippocratic section called **Precepts**, we read how physicians were encouraged "to display the discoveries of the art, preserving nature, not to alter it".[7] From the period of the Renaissance and discoveries of Koch and Pasteur, the science of medicine veered from its belief in the human natural form with the understanding that disease can come from outside the individual's human nature and that scientifically these bacteria attacking the human could be controlled. The result was that medicine was now endeavouring to change the concept of the "art of medicine" into the "science of medicine". The impact of science upon the population made scientific inquiry the religion of its time. Condorcet, a philosopher of the 18th century, wrote

> The improvement of medical practice... will mean the end of infectious and hereditary diseases and illness brought on by climate, food, or working conditions. It is reasonable to hope that all other disease may likewise disappear as their distant causes are discovered. It would be absurd to suppose that the perfection of the human species might be capable of indefinite progress; that the day will come when death will be due only to extraordinary accidents.[8]

The Baconian view of science pervaded the thinking of the 19th century. Science would become man's salvation; therefore it became the moral responsibility of the physician to assume and exercise that power.[9] The physician now became a demi-God. He had within his power the knowledge and the technical skills to control disease. The upshot of this scientific goal was that the principle of medical paternalism was reinforced

by the medical community and patients who needed the physician's expertise.

But the social, economic and political times of the Enlightenment had a different agenda. The scientific revolution was a two-edged sword. On the one hand, it preached for physician power, and on the other the people wanted the power back. The concept of autonomy was a natural phenomenon in this society which yearned for individual freedom and rights. To this day, our federal and provincial charters and constitutions stem from the ideas which pervaded the Enlightenment. In our Canadian and American societies, hundreds, if not thousands, of groups championing individual rights have developed, including women's rights, animal rights, the rights of the newborn and the rights of the physically and mentally disabled. Personal autonomy which developed into the informed consent principle became especially important to the patients. For if the interest and self-determination is available for the healthy citizen in a non-life-threatening situation, how much more meaning does it have to the individuals who have to participate in decisions concerning whether treatment to sustain their well-being will be employed or foregone.

There is a second argument for autonomy. From the time of Hippocrates, medicine has always been recognized as an art. The reality of medicine is that it is not an exact science. Behind the facade of our scientific healing powers are educated guesses called differential diagnoses. For example, there are many different ways of treating breast cancer. Today, medicine offers a wide range of choices; a very debilitating radical mastectomy; a newer modified version where only the breast and lymph nodes are removed; a partial mastectomy or even a lumpectomy. The patient also chooses

between chemotherapy or possible localized radiation treatments. In the face of all this uncertainty, the patient listens to the physician's advice but decides on the basis of her individual and personal values as well.

But there are many problems with patient autonomy. It's not simple. We are concerned with a patient's ability to understand the situation, his/her level of education, emotional and psychological responses which may not be appropriate, how the patient views the doctor, the ability of the doctor to explain the situation, and the rights to second and third opinions which often cloud the medical decision process. And all these issues are in addition to the belief that the medical training, knowledge and experience possessed by the physician is lacking in the average patient. Nevertheless, the weight of argument, opinion and law has shifted tremendously towards the emphasis in patient autonomy.

In our present day codes of medical ethics, we note tensions between principles of beneficence and autonomy in the following:

1. From the International Code of Medical Ethics of the World Medical Association (1983):

   > "The physician shall in all types of medical practice be dedicated to providing competent medical service through technical and moral independence with compassion and respect for human dignity."[10]

2. From the current opinions of the Council on Ethical and Judicial Affairs, American Medical Association 1994, Section 8.08 - Informed Consent:

   > "A patient's right of self-decision can be effectively exercised only if the patient possesses enough information to enable an intelligent choice. The patient should make his/her own determination on treatment. The physician's obligation is to present the medical facts accurately to the patient or to the individual responsible for the patient's care to make recommendations for management according to good medical practice."[11]

3. From the Canadian Medical Association Code of Ethics, Number 12 of the Code reads:

> "Provide your patients with the information they need to make informed decisions about their medical care, and answer all their questions to the best of your ability."
>
> In Number 15 we read:
>
> "Respect the right of a competent patient to accept or reject any medical care recommended."
>
> Number 19 reads:
>
> "Respect the intentions of an incompetent patient as they were expressed (e.g. through an advance directive or proxy designation before the patient became incompetent."[12]

4. From the Catholic Health Care Association of Canada Health Care Ethics Guide. In section 27 we read

> "The informed consent of the patient/resident is necessary for any health care procedure. Informed consent requires that the patient/resident be given all information that could be useful to a reasonable person in the same circumstance, including the benefits, risk and harm of the proposed treatment, of its alternatives and of no treatment at all."[13]

Jewish and Christian Attitudes in the Paternal-Autonomy Debate

As our research will be dealing with the attitudes and communication between physicians and Jewish families at the end of life, we turn now to religious beliefs of the Jewish and Christian communities and how they have influenced thoughts surrounding death. We briefly touch upon the Christian view because it will give us a better perspective as we compare the thoughts of both faiths.[14] It is our assumption that religious faiths play a major role in attitudes towards life and death issues. In fact,

religious or not, the ideology of our culture plays a dominant role in forming and shaping our individual beliefs. This belief is often expressed as a Jungian-cultural response which may even involve generations in the development of personal attitudes. From my experience, it is especially noted in issues surrounding death which sometimes conjure mystical beliefs and older family traditions.

A second consideration in introducing this section is our understanding of how patients, physicians and families may see the debate from their religious perspectives. Associated with these views are various principles, especially those involving the sanctity of life. According to our Judaic-Christian tradition, human beings have intrinsic worth, and therefore life must be saved. The biblical commands of "Thou shalt not kill"[15] or "Love thy neighbour as thyself"[16] are inherently attached to the principle of the sanctity of life.

The problem arises in cases of medical futility. What does religion have to say about intervention when a person is dying. Theologically we may ask, if the Good Lord decides that we should be deathly ill, are we allowed to intervene medically and prevent His will from being fulfilled? Our traditions have claimed that we have the obligation to intervene in order to save life. We cannot fathom the will of the Lord. When the medical profession cannot physically heal the patient, our obligation changes towards the care and comfort of the patient and family.

Indirectly associated with the concept of sanctity of life and comforting the dying is the concept of euthanasia. Euthanasia or mercy killing is defined as "the act of painlessly putting to death persons suffering from incurable conditions or diseases".[17]

Euthanasia thus becomes a personal decision to end life on the part of a patient, physician and/or family. The question is, "Does euthanasia include the medically futile situation where the patient is near death from a natural disease process?" Since the patient will die in any case, would permitting him/her to die at a faster-than-normal pace be included within the concept of euthanasia? The literature would separate euthanasia from futility[18]; however, in most of the cases we have discussed with physicians and families, the perception is that it is a form of euthanasia. Mercifully allowing a patient to die quickly, even though he/she will shortly die in any event, is still considered to be a form of euthanasia.[19] Although we are not dealing with the "pure" sense of euthanasia in which death is deliberately hastened, when families are confronted with cases of medical futility, issues of euthanasia are inevitably brought to mind.

Thus, as we approach religious positions on futility, euthanasia will be included in our discussion because of the perception of the players involved in the decision process.

Catholic Views on Biomedical End-Of-Life Decision-Making

There are twelve major principles which guide Catholic thought in the bioethic decision process.[20] While all these principles are important to the Catholic institution, doctor and patient, the following principles directly impinge on our discussion on futility.

First we have the Principle of Free and Informed Consent. We read,

> "to protect the basic need of every human person for health care and the person's primary responsibility for his/her own health, no physical

> or psychological therapy may be administered without the free and informed consent of the patient or, if the patient is incompetent, of the person's legitimate guardian acting for the patient's benefit and, as far as possible, in accordance with the patient's known and reasonable wishes."[21]

Our reading of this principle is straightforward. The patient, or legitimate guardian, has the right to decide upon treatment. In effect, this is autonomy in its purest form. The doctor must advise the patient of the nature of the proposed therapy, its probable benefits, the possible risks and other possible treatment choices. The patient is then free to decide without undue pressure of time, emotional upset, confusion, persuasion or threat.

The second principle is that of Moral Discernment.

> To make a conscientious ethical decision, one must do the following:
> (a) proceed on the basis of a fundamental commitment to God and the authentic dignity of human persons including one's self;
> (b) among possible actions that might seem to be means of fulfilling that commitment exclude any which are, in fact, intrinsically contradictory to that commitment;
> (c) also consider how one's own motives and other circumstances may contribute to or nullify the effect of the other possible actions as means to fulfil one's fundamental commitment;
> (d) among the possible means not excluded or nullified, select one most likely to fulfil that commitment, and act upon it.[22]

The authors give an example:

> A surgeon faced with the problem of recommending a high risk surgery to a patient will:
> (1) guide his decision by his overriding sense of responsibility before God for the welfare of his patient;
> (2) consider possible ways of treating the patient's condition with or without surgery, and exclude those which are so risky, experimental, or ineffective as to be contradictory to the patient's non-negotiable right to life or other such basic needs;
> (3) also consider whether his judgment might be prejudiced by financial considerations or ambitions to make a name for himself, and whether in

> the circumstances of the patient's life and the available medical facilities, the possible value of the surgery may be nullified;
> (4) among the remaining possibilities, choose and act on one that will most likely benefit the patient and reflect the real concern on the surgeon's part for the patient as a person.[23]

From our understanding of this principle, the surgeon is expected to play a major role in the decision process. He is advised, in number 4 above, that among the possibilities he is to choose and act upon, is that which will likely benefit the patient. We assume that although the physician must receive informed consent from the patient, he is also accountable to choose the right course and act upon it. This suggests that a physician is responsible for the treatment that he administers and it is not entirely up to the patient. Once again, we can envision the physician rights / patient autonomy conflict if the physician feels that the choice a patient reaches is not within the realm of proper medical procedure.

In 1958, Pope Pius XII said in an address to an international congress of anaesthesiologists, that "normally one is held to use only ordinary means for the preservation of life and health - according to circumstances, persons, places, times, and culture - that is to say, means that do not involve any grave burden for oneself and others."[24] At this juncture in Catholic thought, the Pope refers to a paramount distinction between ordinary versus extraordinary care. But to whom was the Pope addressing this distinction? Was it to the doctors or to the patients? Sisella Bok asks this question. She writes,

> To whose choices does it apply? Some hold that all that is ordinary is mandatory, not only for the health professionals but also for the patients. Since life is not ours, but God's, they argue, we cannot abandon it except in extraordinary circumstances, for ourselves or for

others in our care.[25]

A different view holds, on the other hand, that what the patient wants is part of what renders circumstances ordinary or extraordinary.

But perhaps the Pope's approach was universal. He addressed both doctors and patients and this, indeed, is the general Catholic consensus, including Bok's. We may surmise many distinctions. "Ordinary" may mean when we can prolong life and "extraordinary" is when we prolong death. Or, "ordinary" refers to standard treatment such as regular hospital procedures but experimental or highly sophisticated treatment is "extraordinary". Another distinction may be attached to chances of survival or to the quality of the patient's life. The differences may also be noted between invasive and non-invasive procedures, the availability of low or higher technology, expensive or inexpensive financial considerations and short term versus long term survival. The variables seem endless. The upshot is that there has to be an understanding between doctor and patient in the particular circumstances they find themselves. Concepts of what may be considered ordinary in one country or region to a hospital physician or patient may be completely different in another country or region. Each case is weighed on its own merits.

A second, and perhaps more popular Catholic approach, involves the Theory of Proportionalism. This theory advocates Christian beliefs such as the forbidding of homicide but under certain circumstances will permit such acts, for example, when the patient is suffering and it would be inhumane to keep him/her alive under these conditions. Thus, the proportionalists will say, "if the values achieved by the act

outweigh the disvalues or harm caused, then the act is moral even if it violates the generally valid concrete norm. Thus, it is not murder to kill an enemy in self-defense... since I am innocent and he is a criminal. Similarly, the interests of a woman who has been raped may outweigh the value of her unborn child".[26] There have been objections to this theory. It seems to advocate that the end justifies the means, a view which Christianity rejects. Further, how do we measure or weigh the relative values of human actions? In order to answer how this would be determined fairly, the proportionalist may lapse into arguments of utilitarianism and situationalism.[27]

Protestant Views on Bioethical End-Of-Life Decision-Making[28]

Protestant views towards end of life decisions slowly emerged as separate from Catholic doctrine in the seventeenth century. Suicide was generally condemned as contrary to the command of "Thou shalt not kill". Lutheran and Puritan Divines argued that some self-inflicted deaths could have originated with a mental imbalance. Ultimately, it was up to God to decide on each individual's soul. Although other Protestants, including John Locke, a philosopher - not a theologian, continued to condemn self-killing as contrary to nature, a majority view emerged: mitigating circumstances must be taken into consideration and those who take their own lives are at the mercy of God.[29]

Modern Protestants, including Paul Ramsey and Arthur Dyck[30], are also opposed to the morality of self-inflicted euthanasia for the terminally ill, while Joseph Fletcher

and Paul Simmons defended this choice for persons suffering from a painful and fatal disease.[31] All would agree that "passive euthanasia", that is, allowing the patient to die without medical intervention, is permitted when life is being prolonged by advanced technology without the possible restoration of a meaningful quality of life. Ramsey emphasizes that caring for the dying means: 1) stopping useless treatment; 2) never ending life directly; and 3) to care positively, to be humanly present with dying persons.[32] Fletcher does not make this distinction but emphasizes that: 1) suffering is purposeless, demoralizing and degrading; 2) the human personality is of greater worth than life *per se*; and 3) the phrase "blessed are the merciful for they shall obtain mercy" is as important as "thou shalt not kill".[33] Thus, Fletcher emphasizes that the results are important, the results justify the means. Suffering is inhumane and the relief of suffering is a goal permitted under any conditions. Ramsey emphasizes that human conduct is important. Certain acts may not be committed under any circumstance. These involve covenantal relationships between person and person and between person and God.[34]

Once again, questions of definitions and parameters arise about quality of life, passive euthanasia and prolonging life or prolonging death. It is perhaps for this reason that there are many differing views. Generally, the *laissez-faire* attitude of the faith would allow doctors, patients or families to make the final decision in the medically futile situation.

An Orthodox Jewish Position on Bioethical End-Of-Life Decision-Making

In Halachic Judaism, there are two approaches to the futile medical situation which are concerned with any definition of futility. This struggle of definition in Jewish law has plagued the community for centuries. With the advent of newer technological advances unknown to our previous halachists, the situation is more confused than ever before.

Our first approach is taken from a law originating in the Minor Tractate Semachot 1:2-4 which says that a dying person (*goses* in Hebrew) is regarded as a living person in all respects. Moving or touching them is like shedding blood.... this can be compared to a flickering flame. As soon as the person touches it, it becomes extinguished. So too, whoever closes the eyes of a dying person is considered to have taken his soul.

In Rabbi Joseph Karo's Shulchan Aruch (Code of Jewish Law), Section Yoreh Deah 339:1, we read, "if there is anything which causes a hindrance to the departure of a soul such as the presence near the patient's house of a knocking noise such as wood chopping or if there is salt on the patient's tongue; and these hinder the soul's departure, then it is permissible to remove them from there because there is no act involved in this at all, but only the removal of the impediment.

From the above laws, we can deduce the following:

1) Active euthanasia is prohibited. The law emphasizes that touching a dying person or even moving him/her is compared to extinguishing a flickering candle and thus, extinguishing life or murder.

2) From the Shulchan Aruch, we can deduce that passive euthanasia, allowing the patient to die without medical intervention, is permitted. We do not touch the body - just remove some impediment which allows the patient to die quicker.

The former Chief Rabbi of England, Dr. Immanuel Jakobovits, is quick to point out that the term "goses" refers to an individual in whom death is expected to be imminent (three days or less in rabbinic thought). When doctors have given up hope for a patient who may yet live for a few weeks or even a month, it is not considered by Jewish law as a "dying situation" and therefore passive euthanasia would be forbidden. He further argues that the removal of impediments as described by the Shulchan Aruch, is not analogous to any part of the therapeutic armamentarium employed to keep the patient alive unnaturally as one would find in an ICU. However, the discontinuation of life-support systems which are specifically designed and utilized in the treatment of both curable and incurable patients might only be permissible if one is certain that in doing so we are shortening the act of dying and not interrupting life. We have to make the fine distinction between prolonging life and prolonging death. The former comes within the physician's reference, the latter does not.[35]

In providing Judaic principles directly involving futility, we turn to an article from J.D. Bleich. He give us an insight to a Jewish perspective on the Karen Ann Quinlan case, perhaps known as one of the classic case debating futility in our times. Briefly, Ms. Quinlan, a PVS (permanent vegetative state) patient was hospitalized in New Jersey, her life being maintained by a respirator. Her parents requested that the hospital remove the respirator. The case went to the courts and the Superior Court judge ruled

that to remove the respirator would be tantamount to murder. We emphasize, Bleich's view is only a single position, not the view of all Jewish denominations. Further, the following axioms are basic principles and even within the framework of Halachic Judaism they are not etched in stone. There are shades of grey within each principle which are debated. We quote extensively from the article[36] because these principles will be noted throughout our thesis especially as expressed by our families we interviewed.

Principle 1: Only the Creator who bestows life can take life.

> It is quite true that man has the power to prolong life far beyond the point where it ceases to be productive or pleasurable. Not infrequently, the patient who is capable of expressing his desires and allowed to follow his own inclinations, would opt for termination of a life which has become a burden both to others and themselves. Judaism, however, teaches that man does not enjoy the right of self-determination with regard to questions of life and death. Generations ago, our sages wrote:
>
> "Against your will you live; against your will you die."
>
> ...They (these words) may be taken quite literally as an eloquent summary of the Jewish view with regard to both euthanasia and withholding of life-sustaining treatment.... Only the Creator who bestows the gift of life may relieve man of that life even when it has become a burden rather than a blessing.... In Jewish law and moral teaching, life is a supreme value and its preservation takes precedence over virtually all other considerations.

Principle 2: The physician as healer is only obliged to prolong life.

> Distinctions between natural and artificial means between ordinary and extraordinary procedures, and between heroic and non-heroic measures occur within the Catholic tradition, but no precisely parallel categories exist within Jewish law. Judaism knows no such distinction and indeed the very vocabulary employed in drawing such distinction is foreign to rabbinic literature. Rambam (Maimonides), in his commentary on the Mishnah, Pesachim 4:9 draws a cogent parallel between food and medication. God created food and water; we are obliged to use them in staving off hunger and thirst. God created drugs and medications and endowed man with the intelligence to discover their medical properties; we are obliged to use them in warding off illness and disease. Similarly,

> God provided the materials and technology which make possible catheters, intravenous infusions, and respirators; we are obliged to use them in order to prolong life.... The physician's duty does not end when he is incapable of restoring lost health of his patient. The obligation "and you shall restore him" (Deuteronomy 22:2) refers, in its medical context, not simply to restoration of health, but to the restoration of even a single moment of life.

Principle 3: The only exception which permits a "passive" death is the law of Goses, moribund patient who was in the midst of death throes.

> The sole exception to these principles which Halacha recognizes as a case of a Goses, a moribund patient actually in the midst of death throes (death expected within 72 hours). The physiological criteria indicative of such a condition must be spelled out with care. It is surely clear that a patient whose life may be prolonged for weeks and even months is not yet moribund; the death process has not as yet started to commence and hence the patient is not a Goses. Halachic provisions governing care of a Goses may most emphatically not be applied to all who are terminally ill.

Principle 4: Terminating medical treatment is a religious and moral decision.

> To depict any human condition as hopeless is to miss entirely the spiritual dimension of human existence.... Even if it were true, that medical diagnoses and prognoses are infallible, the decision to terminate treatment is not a medical decision; it is determination of a moral question. That the physician possesses specialized knowledge and unique skills is unquestionable. However, his professional training guarantees neither heightened moral sensitivity nor enhanced acumen. He may, quite legitimately, draw medical conclusions with regard to anticipated effects of the application or withholding the various therapeutic procedures, but the decision whether to proceed or not to proceed is a moral and not a medical decision... He has decreed that we must love, cherish and preserve life in all its phases and guises until the very onset of death. While even terminal life is undoubtedly endowed with other meaning, and value as well, subservience to the divine decree in fulfilment of God's commandment is, in itself, a matter of highest meaning.

Principle 5: There is no validity to death with dignity.

> The coining of the phrase "death with dignity" by advocates of passive euthanasia was a stoke of genius. Opponents of such practices are immediately disarmed. Everyone respects "rights" and no one decries "dignity". Yet, while repeated use of a glib phrase by the press and

> media may influence attitudes, the coining of a cliché is not the same as making a case. Is a sickness or frailty, however tragic, really an indignity? Is the struggle for life, in any form, an indignity? Is it not specious to insinuate that the attempt to sustain life is aught but the expression of the highest regard for the precious nature of the gift of life and of the dignity in which it is held?

William May has a similar argument on the term "quality of life" which influences societal attitudes for acute medical care, but only grudgingly for rehabilitative or chronic care.[37]

But there are further ethical and philosophical questions which arise and are very close to our futility problem. If any positive action which actively leads to the ending of a human life is defined as murder, where is the precise dividing life between permitted passivity and passivity in the halacha which is an immediate cause of death? Is withholding food or oxygen or insulin to a diabetic considered a passive procedure or does it cause death? What is the status of an artificial respirator? If we stop an artificial apparatus which is supporting the life of a terminal patient, has one passively removed an impediment to death, or has one actively killed the patient? Is there a role for quality of life in Judaism, and how do we decide on quality of life? Is the physician always obligated to provide inappropriate therapy just to keep the patient alive a little longer? Is a patient obligated to accept all medical treatments, even if the medical situation is hopeless? What is the law if there is pain and suffering? How does Judaism resolve the conflict between the sanctity of life and relief of human suffering? Is there a point in quality of life beneath which life has no sanctity? Is such a life no longer of infinite worth? How do you decide whether you are shortening the act of dying or not interrupting life?

All these questions are not theoretical. Every day they come to life in intensive care units, from the neonatal to the surgical, on medical and palliative care wards. They involve children, teenagers, the middle-aged and elderly. I witness them and, together with religious families, struggle with them daily. Doctors, families and patients have to make life and death decisions and live with their aftermaths. Most often these include orders surrounding resuscitation and other medical interventions in critical care. As one ICU nurse pointedly said to me, "There is no pleasure when we are forced to play God".

Summary

I have endeavoured to underscore the problem of futility from the beginning. We have seen, historically, from the first of the Hippocratic codes to our present medical codes, a gradual change from the physician-paternalistic approach to patient involvement in the decision process. It is only within the last twenty-five years that most institutions and hospitals insist on the policy of patient's informed consent. These changes from physician paternalism to patient autonomy, in one form or another, have now become the major issues and battleground for the futility debate.

Confusing the issues is the ambiguity of definitions. How do we define autonomy or paternalism? And although the codes generalize these terms, they have omitted many concepts which need clarification. What are the physician's rights and what exactly is informed consent? How "informed" does the patient have to be? The codes involve prolonging life or prolonging death, but how do we define these terms? How do we

define quality of life and dignity in death? And what about issues of morality involving physicians' omission or commission, ordinary versus extraordinary means, or procedures which are direct or indirect? How do we define these issues? We also have to contend with physician and family rights and duties and who makes the decisions and how to carry out the decisions.

I have only briefly noted bioethical end of life decision-making from the Christian and Jewish points of view. For religion, end of life decisions are primarily moral issues, which, in a way, makes the decision process easier. We take the argument out of the hands of the individual and refer to the philosopher, moralist and theologian. Theoretically, end of life medical ethics now has a foundation, legs to stand on. Practically, in real life situations, patients and families look towards the physician's decisions. Secular ethics demands that societies create the definitions which is most difficult, while ethics also seem to shift from generation to generation and profound differences are found in different geographic locations.

This is emphasized by Daniel Callahan as he crosses borders between Europe and the United States showing that American tendencies to perform coronary artery bypass grafts on patients over eighty years of age are almost unheard of in Switzerland. Callahan compares this approach to the strong sense of American individualism which makes an embrace of common and shared values difficult, if not impossible.[38]

Given that we have different values of what should be done, without any clear consensus on the above issues, it behooves us to think about our medical ethical principles and concepts surrounding end of life decisions. Many newer forces have

joined the equation, including social, political, economic, government control, advances in technology, family involvement and the average age of our patients which now nears eighty. The debate has absorbed us. We find ourselves continually debating the problem but any form of consensus has eluded us. In our next chapter, we will endeavour to clarify and define the issues and discuss some of the attempted solutions. Towards the end of the chapter, we move away from principles into an understanding of process. Simply put, it's not which principle is right or wrong. In the end, it's the ethical communication process between the players which will prevail.

Notes

1. Laurence J. Schneiderman, Nancy S. Jecker and A. R. Jonsen, "Medical Futility: Its Meaning and Ethical Implications", *Annals of Internal Medicine* 112, no. 12 (1990): 949-954.

2. Bruce E. Zawacki, "The *Futility Debate* and the Management of Gordian Knots", *Journal of Clinical Ethics* (Summer 1995): 112.

3. Many physicians would argue that the conflict is between the principles of beneficence and autonomy. We chose "paternalism" because this is how patients and families view the conflict as they face the physician.

4. Stanley Joel Reiser, Arthur J. Dyck, William J. Curran. Ethics and Medicine (Cambridge, Massachussets: MIT Press, 1979), 5.

5. *Ibid.*, 6.

6. Source Unknown. Fred Rosner, in his chapter titled "The Physician Prayer" in Medicine in the Bible and the Talmud claims that it was written in 1783 by Marcus Herz, a prominent German physician (1747-1803). Rosner concludes "From all the foregoing discussion, the evidence overwhelmingly favours the concept that prayer attributed to Maimonides is a spurious work... Absolute proof that this is so is however lacking and may never be discovered." Fred Rosner "The Physician's Prayer" in Medicine and the Bible and the Talmud (New York: KTAV Publishing, Yeshiva University Press, 1977), 135-136.

7. Reiser et al., 6.

8. J.M. Condorset. A Sketch for the Historical Picture of the Progress of the Human Mind (London: Weidenfeld and Nicholson, 1955), 235.

9. Nancy S. Jecker. "Knowing when to stop: The limits of medicine", *Hastings Centre Report* 21, no. 3 (1991): 5-8.

10. Warren Thomas Reich, The Encyclopedia of Bioethics (Simon Shuster and Prentice Hall International, 1995), vol. 5, Appendix p. 2647.

11. *Ibid.*, Appendix p. 2664.

Even within this policy from the AMA, we note conflicting principles. See section 2.035 where it states "Physicians are not ethically obligated to deliver care that, in their best professional judgement, will not have a reasonable chance of benefitting their patients. The patient should not be given treatment simply

because they demand them. Denial of treatment should be justified by reliance on openly stated ethical principles and accepted standards of care..... not on the concept of "futility", which cannot be meaningfully defined. (Reich et al, p. 2654)

12. Code of Ethics, Canadian Medical Association, 1996.

13. Reich et al. Appendix p. 2698.

14. We also acknowledge that we are only presenting a single view of the Jewish faith. There are many denominations within each faith with differing views. Even within each denomination, there are always shades of differences. We are presenting a traditional Orthodox Jewish view.

15. Exodus 20:13.

16. Leviticus 19:18.

17. Webster's Third New International Dictionary (1965), s.v. "Euthanasia" or "Mercy Killing".

18. Douglas M. Sawyer, John R. Williams and Frederick Lowy, "Canadian Physicians and Euthanasia: Definitions and Distinctions" *Canadian Medical Association Journal* 148, no. 9 (May 1, 1993): 1463-1466.

19. It is, perhaps, this perception which has prevented the Canadian Medical Association from officially endorsing euthanasia. Euthanasia and futility overlap and we do not have any clear consensus on handling futility.

20. Benedict M Ashley and Kevin O'Rourke, Ethics of Healthcare (St. Louis, Missouri: Catholic Health Association of the United States, 1986).

21. *Ibid.*, 88.

22. *Ibid.*, 88-89.

23. *Ibid.*, 89.

24. Pius XII, "The Prolongation of Life", *The Pope Speaks* 4 (1958): 395.

25. Sisella Bok, "Death and Dying: Euthanasia and Sustaining Life" in Reich, Warren Tednor, Encyclopedia of Bioethics (New York: Free Press, 1978), 271.

26. Ashley and O'Rourke, 84.

27. *Ibid.*, 84-85.

28. Although the subject of "futility" is not directly discussed, we take our direction from the Protestant attitudes towards euthanasia often derived from medically futile situations.

29. Gary B. Ferngren. "The Ethics of Suicide in the Renaissance and Reformation", in Suicide and Euthanasia: Historical and Contemporary Themes, ed. Baruch Brody (Dordrecht, Netherlands: Klewer Co., 1989), 155-181.

30. Arthur J. Dyck, "An Alternative to the Ethic of Euthanasia" in Ethics of Medicine, eds. J. Reiser, A. J. Dyck and William Curran (MIT Press, 1979), 529-535.

31. Paul Ramsey, The Patient as Person: Explorations in Medical Ethics (New Haven: Yale University Press, 1970): 118-160.

    Also: Paul D. Simmons, Birth and Death, Bioethical Decision-Making (Philadelphia: Westminster Press), 193-246.

32. Paul Ramsey, 118-160.

33. Joseph Fletcher, On Morals and Medicine (Boston: Beacon Press, 1960), 189-210.

34. Richard A. McCormick, "Bioethics and Method: When Do We Start?" in On Moral Medicine, eds. Stephen E. Lammers and Allan Verhey (Grand Rapids, Michigan: Wm. B. Erdsman Publishing Co., 1987), 45-55.

35. Fred Rosner, "The Jewish Attitude Towards Euthanasia", Jewish Bioethics, eds. Fred Rosner and J. David Bleich (New York: Hebrew Publishing Co., 1979), 264.

36. J. D. Bleich, "The Quinlan Case: A Jewish Perspective", Jewish Bioethics, eds. Rosner and Bleich (Hebrew Publishing Co. 1979): 266-276.

37. William May, The Patient's Ordeal, 121-141.

38. Daniel Callahan, "Necessity, Futility and the Grand Society", *Journal of the American Geriatric Society* (1994): 866-867.

CHAPTER II

FUTILITY: EXAMPLES, DEFINITIONS, PROPOSED SOLUTIONS, AND CRITIQUES

This chapter will focus on four areas. First, I will offer case examples of medical futility over the hospital landscape, presenting the scope of the problem. There is hardly a hospital patient area immune to the futility issue. Second, I will present four major approaches, or models, which address futility through the reasoning of eight ethicists. I will begin to note the difficulties in defining and resolving the futility debate. Third, I will offer a critique of these approaches and, finally, give a brief introduction to the collaborative model.

The paternal/autonomy debate can, perhaps, be better conceptualized through a description of some case illustrations. The description of these cases will avoid medical terms concerning the patient's physical history, diagnosis, interventions and complications which led to the medically futile situation. Rather, I will stress the attitudes, sentiments and responses of the physicians and families towards futility. The goal is to examine and compare these responses in order to give a fuller understanding of how to manage the problem. The parameters which describe cases are: (1) the physician says further treatment would be futile; (2) the outcome is described as bleak, for even in the best of circumstances when the patient is not in pain, there is no hope for physical survival; (3)

the doctor calls the family to a meeting and says, "At this point, there is nothing further to be done. We are only prolonging the death of your father."

The example in Chapter I of the Jewish lady and her family taken from the ICU situation is but one of the cases in which the paternal/autonomy conflict takes place. Perhaps it is in the ICU area where the medical armamentarium is most notable. Families seem to absorb the frontier mentality, hoping that these machines, state of the art equipment, will save the patient's life. It also engenders the debate more often because ICU beds are at a premium and long-term care in the ICU is unacceptable.

A second example is futility in CPR (cardiac pulmonary resuscitation) when such intervention is not recommended by the physician. In these cases, the patient is usually aware of the situation and of his diagnosis. According to most hospitals' critical intervention policies, patients must be asked if they want to be resuscitated if their heart stops functioning. Patients are given an explanation of the futility in the situation, and the probable outcome and are asked their opinion about what they would want done. Depending upon the protocol, these questions must be asked on a regular basis - in case patients change their minds due to shifts in physical, mental and personal situations. In practice, this is most difficult. First, it is uncomfortable for physicians to talk in general to dying patients. Second, to ease the situation, the physician usually involves the family. This, today, is common procedure[1], despite textbooks which emphasize *not to involve the family unless instructed so by the patient.*[2] When, and if, the patient says, "I want to be resuscitated" while the physicians disagree, quite often two physicians will sign the DNR order despite patient and family disagreement. In this way, the DNR

order becomes official hospital policy. In most cases, there is communication between family and physician and it is usually resolved in accordance with the physician's request. The futility problem will also arise when families find out that a DNR order was written without the consent of the patient or family. I hear, "Rabbi, this is arrogance at its highest level. How dare they decide for themselves what should be done to my father!" Or, if it is a family of a Holocaust survivor, they may say, "They are no better than the Nazis. They do what they want and we have to stand by and watch."

A third example is futility in the beneficence/burden scale within the operating room situation. Here we have a 90-year old gentleman ill with a bowel obstruction gradually becoming weaker in his hospitalization. Families and physicians discuss the patient's chances of survival in the operating room. The physicians and surgeons advise against the operation. The family and patient want to take the risk. At this point, they are concerned with prolonging life or death and they enter into the numbers game. First there is the risk of our patient not surviving the operation. If he/she does survive it, is it worth the post-operation pain and short-term survival? The question, then, involves percentage points and exactly what short-term survival means to the physician, family and patient. Decisions may be made along the following lines. If the family requesting the surgery is well-known to the physician, the physician may attempt the surgery. He doesn't want to disappoint the family. If the surgeon does not know the family or patient, he may suggest finding another surgeon. Sometimes we hear, "I'm doing this against my better judgment. The family refuses to realize what the patient will have to go through if he/she makes it - and for what?"

PVS (persistent vegetative state) is our fourth example. This would include families who insist on continued use of mechanical ventilation and artificial feeding of the comatose patient when the physician and staff argue that to do so is an inappropriate, unnatural and futile intervention. The families, however, are often reluctant to "starve" their parents or "cut-off their air supply". This is especially exacerbating after the tubes have been in place and the doctor suggests removing the apparatus.

The fifth paradigm is fairly common. It is the patient with metastasized cancer with no hope of medical cure. The ICU has been requested to take the patient but refused on their standards for admittance. They do not accept cases which have no chance for cure. The family becomes upset. They begin to look for second and third opinions. In turn, the physicians are perturbed at being challenged unfairly. The family may look to alternative approaches. The physician may suggest moving the patient to another hospital. The Jewish family might counter that they want kosher food for their parents, unavailable in other hospitals.[3] The physician suggests palliative care - which is refused. The situation becomes antagonistic. Blame and bitterness begin to take over. The patient becomes acutely ill in other areas, such as kidney function. The family asks for dialysis. The doctors refuse. The extremely sad part sometimes occurs when they are told of some physician, usually in the United States, who has a miracle cure. The family may then spend thousands of dollars for physician and hospital expenses to no avail.[4]

Our sixth case usually happens when the patient in the ICU has been diagnosed as brain dead. After a couple of days, the physician approaches the family.

"As you have been advised, your father/husband is, according to all tests, brain dead. There is nothing more we can offer. Perhaps the time has come to disconnect the respirator. For all intents and purposes, your father/husband is already legally dead and it's just a matter of completing the process."

The family counters,

"But doctor, he is breathing. His heart is pumping, and when you extubate and remove the tubes, you will be killing him."

The physician replies,

"He really doesn't have a chance of survival. The brain is connected to the respiratory system and if the brain is dead, it is only the machines that are keeping him alive."

The family argues,

"But look at him, Doctor, he is alive. We have heard of cases - we just can't agree with you at this time."

There are cases which are on the fringe of futility. The doctors sense frustration knowing that the patient will not improve. The families, too, experience helplessness. Very little can be done to improve the patient's physical health. This is seen in the treatment of Alzheimer's patients who become ill and cannot be treated and cured. The doctor leaves the room and whispers to me, "Rabbi, what the hell are we doing here? I know what you are going to tell me, but look at this man. He doesn't even know that he is defecating on the floor. He doesn't know if it's day or night. He doesn't even recognize his family. What the hell are we doing?"

Then you have the geriatric patient brought into Emergency with a serious case of pneumonia, weak, lungs filled with water, only able to breathe with oxygen. He's approaching 90 years of age. In good times, he uses the walker to get to the bathroom.

In simpler cases of pneumonia at that age, it takes weeks to cure. The doctor argues, "Rabbi, this man doesn't have a chance. It's a crime to prolong his life."

Another case could be the stroke patient. Here we may have a gentleman, middle-aged, in his early sixties, bedridden, unable to communicate. His wife visits every day, nurses him, reads to him, caresses him. She believes he understands his surroundings and what is happening to him. His eyes are always open, staring at the ceiling. The television is open for hockey games and other shows he used to love. Suddenly he has a spasmatic attack. The doctor is called in. He expertly calms the situation. He leaves the room shaking his head and mumbles to me, "Rabbi, this is not medicine. This is prolonging death, not life. They shoot horses, don't they?"

Instinctively, connected to the futility concept is the search for a "quality of life". The problem is, How do we measure quality of life? Who has the right to measure quality of life? Who is to have the final decision on quality of life? These thoughts are part and parcel of the issues noted by families, patients and physicians when confronting the futile situation. The following two sections endeavour to deal with these questions.

The Problems in Defining Futility

As we proceed, we shall see that defining futility is a most difficult challenge. We will learn from our ethicists and their approaches to the debate that it is not only a medical concept, but involves ethics, philosophy, research, psychology, legal issues, societal values, religion and cultural beliefs. The saddest part is that we are torn with

indecision in an important issue which may affect all of us at the end of life. As one exasperated ICU physician once told me, "Rabbi, I sometimes feel we are playing with semantics. I am telling you *the buck stops here* and if it doesn't stop here, we may as well close the hospital!"

But let us take a step backward and examine medical goals and the players who are the stakeholders involved in the debate. Futility is intrinsically attached to the goals of medicine. When these goals, however we define them, are unattainable, the physicians will tell us that further medical intervention is futile. It used to be that preserving life or curing disease was a major medical goal. Today, with our capacities to lengthen our lifespan, we are concerned with newer issues such as defining the quality of life.[5] Generally, the longer we live, the poorer our quality of life. Years ago, our goals included discharging the patient from hospital so that he/she could go home. Today, we are concerned with the question, "Who will take care of the patient at home?" Governments have organized CLSCs but they aren't prepared for the numbers. Some would like to believe that patient independence is a goal of medicine, but what do we do with the millions of aged Canadians who cannot be independent? There was a time when benefitting the patient was a goal. Today, we ask, "Who decides if the patient has benefitted?" Is it the patient, doctor, government, hospital administration or family? And as we introduce government and administration into the health care equation, patients and families feel that their sense of autonomy is compromised. They cannot any more make final decisions which will affect their physical well being.

Primarily, it is the last of these questions which describes the problem in any

definition of futility. Physicians, patients, hospital administration and families may all have differing opinions on the definition of futility in any particular case. For example, if the patient is 87 years of age and in the last stages of dying from cancer, and a new chemotherapeutic medication costing $30,000 could prolong his life another month without pain or suffering, physicians may have doubts whether prolonging life is worth it in this case. They might ask, "Are we prolonging life, or prolonging death?" No one dares approach the patient who, we know, wants to live. The hospital administration may say, "This is crazy. It costs a fortune. We could hire another nurse for this kind of money." The family feels that the hospital should save the patient. "A month is a long time. How could you ask such a question? Where is your compassion?" Thus, changes in technology, the doctor/patient relationship, individual rights and government control have left us a legacy of confusion and conflicting values and the difficulty in defining futility. The physicians may say futility is when we prolong death (whenever that may be). Families may argue that futility is when prolonging life is impossible (whenever that may be). Hospital administration may reason that futility is when a patient is over 85 years of age and it is not financially feasible to continue further treatment (whatever this means). It is in this context of confusion and conflict between the stakeholders that we approach the next section.

The Current Approaches and Models on Futility

In this examination of the different criteria and models of futility, I have primarily

culled the views of various medical ethicists who discussed the ethics of futility at a Congress sponsored by the American Geriatrics Society in March 1993. Their papers appear in the *Journal of the American Geriatric Society* (Volume 42 in August 1994). Their points of view can be divided into four areas:

1. Those who favour the physician and professional integrity. (Laurence Schneiderman and Howard Brody)
2. Those who favour self-determination by patient and/or family. (Robert Veatch and James Lindemann Nelson)
3. Those who argue for justice and that society must come forward with answers which would distribute resources more effectively through shared deliberations. (Donald J. Murphy and John D. Lantos)
4. Those who emphasize that there should be a constructive dialogue between families, patient, and physician. (Bruce Zawacki and Stuart J. Youngner)

Schneiderman on Futility

Schneiderman defines medical futility as the "unacceptable likelihood of achieving a therapeutic benefit for the patient".[6] The emphasis is on the terms "benefit" and "patient". The physician's responsibility is to provide not merely an effect on some part of the body, but a benefit to the patient as a whole.

This definition is based upon the guidelines offered by the Hastings Center[7] that make a distinction between physiological and non-physiological futility. Physiological

futility is when further treatment will provide no physiologic benefit to the patient. In such instances, the medical profession has no obligation to provide it. Non-physiological futility is when a professional uses a value judgment to decide that although a treatment will have a physiological benefit, this benefit is not sufficient to warrant giving the treatment. This is the concern Schneiderman et al have when they seek to benefit the patient as a whole. In other words, it has to "be worth it" for the patient's quality of life in that the patient will appreciate the efforts of the physician to warrant further treatment.

Schneiderman et al have refined the Hastings Center definition by dividing futility into two components: quantitative and qualitative. From the quantitative view, they argue that if a treatment in the last 100 cases has not worked in a specific situation, it will almost certainly not work if it is tried again. With this approach, the empirical evidence gives the physician a reasonable consensus that aggressive treatment will not work and, therefore, that it is futile. Qualitative futility is based on the premise that the goal of medicine is to return the patient to a reasonable quality of life which is appreciated by the patient. If the patient is in an irreversible coma or a vegetative state, intervention would be considered futile. This qualitative approach differs from many others that measure success in treatment if the patient can be released from the hospital.[8] Schneiderman does make exceptions. He permits a physician to inform the patient of the diagnosis, prognosis and treatment plan, but warns the physician not to make the mistake of creating any exchange which would allow the patient to decide on a treatment option. Another exception calls for compassion where prolongation of death is permitted so that the patient will have a last visit from a distant loved one hastening to the bedside.[9]

Howard Brody on Futility

Brody begins his discussion of futility with an assumption that autonomy has won the paternalism/autonomy debate. He argues for an expanded role of the physician with some qualifications. The crux of his argument is the following:

> The physician must decide unilaterally whether a treatment possibly comes up to the mark as proper scientific medical practice... The moral value at stake here is the internal integrity and coherence of a professional practice and maintenance of its internal standards of excellence... Someone who calls himself a physician but is constantly willing to compromise on valid modes of treatment in order to satisfy the wishes of the patient is a fraud. When an intervention is futile, the physician may, and indeed should, withhold it, regardless of the patient's requests.[10]

When presenting his paper at the Geriatric Conference, Brody explained:

> Why does a proper understanding of patient autonomy accept, and indeed require, the limits on patient choice imposed by professional integrity? The answer lies in what patients seek from physicians, in what they autonomously request or refuse. If all that they want is advice from some scientifically informed person about which manipulations will or will not produce certain biological results, then professional integrity is of little consequence (except for the stipulation that the *expert* does not lie to the client).[11]

The only difference between Brody and Schneiderman is that Brody offers a set of rules concerned with the physician's violation of integrity. Schneiderman et al will leave every decision up to the physician, claiming that no physician standards should be set from without the medical profession.

Robert Veatch on Futility

Veatch, at the other extreme of the futility debate, claims that physicians have no right nor acumen to decide on futility. Bleich, too, argued as above[12] that in the Judaic view, decisions on futility belongs to philosophers or religious authorities. For Veatch, however, futility depends on the Theory of the Good and there are varying aspects of the total good including the psychological, social, economic, legal, religious, familial and educational. The physician's expertise is only considered in the realm of medicine, but he lacks the expertise which takes all the spheres of the good into account. Veatch writes, "Deciding what is a good outcome (for the patient) is contingent only in part on what is medically good. No one believes that the total good is limited to the medical or organic sphere. The overall good will include many spheres such as the psychological, the social, the economic, legal, religious, familial and educational. Deciding whether a good is served would require expertise in all of these spheres and no one is foolish enough to claim that the clinician is an expert in all these areas."

Veatch is also concerned about ambiguity in the clinical use of futility. First, there are linguistic misunderstandings of the term. Some physicians may invoke futility only if the chance of cure is less than 1%, while others go up to 13%. Second, surrogates may have different conceptions of futility. Even the way it is presented to the surrogate often hides a value-laden statement. For instance, if the physician assumes some probability level (e.g. a 5% chance of cure) he/she may be making further statements to the surrogate about the ineffectiveness of the proposed treatment. What the

physician should actually say is, "according to statistical probabilities, perhaps 1 in 20 would survive the treatment". In this way, the surrogate may have a better understanding of the probabilities.[13]

Veatch also argues

> "Some lay people may accept different rules of evidence, different ontological and epistemological assumptions or different conceptual paradigms. If they do, a clinician cannot claim the ability to know what the effect of the treatment will be unless he/she could also claim to be definitely authoritative on these essentially non-scientific questions. If I am right that clinicians have no special authority for making such claims, then they cannot even claim expertise in any definitive way when it comes to knowing what the effect will be."[14]

On a different issue, Veatch gives an example of the Orthodox Jew's claim to life-prolonging ventilation or medically supplied nutrition for the PVS patient, even if these interventions are medically valueless. He writes,

> The alternative is to hold that even though a treatment that would prolong life is desired by a patient, the physician can judge that the patient would be better off dead. I don't know how anyone could have the hubris to afflict death paternalistically on a patient against his or her wishes.[15]

Veatch does concede that while there is a right for patients to refuse treatment, it cannot under all circumstances give him a right to access to treatment. There are rights of the physician as well. In using the principle of justice, however, Veatch does entitle the patient to the right to access, even in futile cases, under certain conditions. Some of these include interventions that are fundamental to health care, clearly not frivolous. Second, the principle of justice would claim that such care would be subordinate to claims of other patients who are worse off. Third, only cases involving ongoing patient/physician relationships are considered.[16] In conclusion, Veatch asks

clinical societies to contribute to the futility debate by encouraging society to set the criteria for futility and refraining from imposing their idiosyncratic judgements on patients and surrogates who disagree. This is where Veatch differs from Bleich. Bleich would follow the Torah law as interpreted by Orthodox Judiasm before making any decisions.

James Lindemann Nelson on Futility

Whereas Howard Brody claimed that in the futility debate, patient autonomy was trumping physician rights, Nelson claims that invoking futility takes the decision-making process from the patient and gives it to the physician. This is more evident when the patient is incompetent and futility is invoked in the face of the family. We are then concerned with the best interests of the patient and substituted judgment. Some of the literature suggests that families are often unable to prove what the patient would have really wanted.[17] Thus, in such circumstances, the argument for the physician may be justified. The physician may then withhold treatment as he/she sees fit despite family objections.

The futility argument also appeals to professional integrity and, in fairness, we also have to consider two important questions. First we may argue that when we examine futility, we are really looking at a procedure. Is this a worthwhile procedure? Perhaps we are not involved in a categorical determination of whose life is worth it or not, but what constitutes a medical benefit. Second, even if we disregard rationality

issues, there remains a burden benefit factor for all who are involved. As an example, Nelson recalled the case of Mrs. Helga Wanglie. Mrs. Wanglie was an 86-year-old woman who had been dependent on mechanical ventilation and in a persistent vegetative state (PVS) for more than a year. Her husband insisted that she believed in maintaining life at all costs and that "when she was ready to go... the good Lord would call her". Her physicians, on the other hand, believed that the continued use of mechanical ventilation in intensive care was futile. When attempts to transfer her elsewhere failed, they sought to have the court appoint an independent conservator with responsibility for making medical decisions on her behalf. A judge denied this petition and re-affirmed the authority of her husband as legal surrogate. In using the Wanglie case, Nelson argues that procedural and substantive issues are inter-connected. The judgment and procedure must involve whether this life is worth it or not. Judgments of deciding about the odds in a burden/benefit calculation are also judgments about the value of life. Even if the physician in all sincerity and integrity feels that it was not worth keeping Mrs. Wanglie alive under these conditions, to enforce this would be to allow the profession the right to decide on whose life is worth living or worth suffering.

Nelson then states his position to recognize the family's authority. Since the major problem with futility is whether the patient's life is worth maintaining, the family is in the best position to decide because they have some intimate sense of what a meaningful life is all about in the family, and because of their relationship of care and concern, they may actually contribute to creating that meaning. Mrs. Wanglie was a person. Nelson asks, "Is a person only a sentience and intelligence, or is a person

essentially constituted by relational processes extending through time which find their special situations in contexts of intimacy?" The kind of life that was left to Mrs. Wanglie in the judgment of her family was worth supporting, even though her physicians and much of the rest of society disagree.[18]

Whereas Veatch talks about the physician's deficiency in expertise regarding the "theory of the good", Nelson talks of family values and the physician's lack of knowledge of the family constellation and meaning of death for the family and patient. Quality of life has two components for Lindemann. The first is the objective component. This is primarily seen by the physician, wherein the physician measures the patient's quality of life before and after any intervention. In cases of futility, the physician decides that there is no point in further intervention. The family seeks a second subjective component in the quality of life which is the personal meaning of life for the patient and family. The feelings of love attached to relationships are difficult to measure and can only be experienced by the family. Death can be devastating to many families, taking many years, if ever, to make the necessary adjustments. Physicians are usually aware of this, but do not know how to respond professionally. Some physicians show compassion, others do not. Some physicians seem to be paralyzed, leaving the family to fend for themselves. For most, death has always been the enemy, a sign of failure. Thus, in most cases, the extremely busy physician opts out of the situation.

Donald J. Murphy on Futility

Murphy is candid and straightforward in his approach.

> Money matters. Financial incentives influence a clinician's behaviour. Any seasoned clinician who looks honestly at the profession knows that the role of financial incentives is probably greater than the medical literature suggests. Guidelines that account responsibilities for the influence of money (or time) will be more useful than those who ignore these influences... Money represents the conflict of interest clinicians must live with everyday. Not all these conflicts have financial implications, but most do. Time costs money. Diagnostic tests cost money. Detailed notes cost money. Responsible guidelines should account for the reality of financial incentives and the inevitable conflicts of interest that clinicians deal with routinely.[19]

At the Geriatrics Symposium, Murphy argued,

> Schneiderman and Jecker suggest that futility should not serve as a devious rationale for reducing medical costs. I agree. It should serve as an explicit rationale for reducing medical costs... a fundamental change in our culture. To say no and set boundaries around patient autonomy - will be necessary to sustain cost control measures. Institutions that are serious about cost control must address futile care and learn to say no.[20]

Those who argue, like Murphy, that the allocation of resources is part and parcel of the futility debate are gaining adherents, especially from government and hospital administration which seek fiscal control. The case mentioned above about the gentleman who could have had his life extended at very high cost is an example of what's happening in health care. It is tempting and considered honourable for most of us to separate futility from scarce resources. In a civilized society, we believe that physicians are expected not to gauge life by the economics of the situation. The problem is that this is not an easy road to follow. Beneath our ethical dilemmas as in end of life lie issues of costs. The Canadian health care system is not as susceptible to financial interests as the

American system; however, to argue that it has no influence is like burying our head in the sand.

John D. Lantos on Futility

Lantos ties the futility debate to the political and economic developments in medicine over the last ten years in the United States. He argues that the prospective payment system, inaugurated by insurance companies, allows hospitals and physicians to categorize and measure marginally beneficial treatments according to profit and loss. Studies showed that American hospitals could lose $23,000 per patient who requires 72 hours of ventilation. Patients who die of diabetes or heart failure are only profitable to the hospital if they die within a week. Further studies showed that providing nutritional support for 266 patients led to a net loss for a hospital of nearly $1 million.[21] In the years before prospective payment plans, the more service hospitals and physicians provided, the more money they made. Today, the concept of futility in hospitals has arisen because of the newer financial pressures and burdens. There is now an incentive to deem certain illnesses and therapies futile and thwart any legal right a patient or family may have to demand "unreasonable" care. The Canadian Medicare system, tightly budgeted by federal and provincial governments, is under the same strain. Patients are rushed out of hospital often before they have fully recovered because of governmental pressure. CLSCs (Centres locaux de services communautaires) have been created to keep people out of hospitals. Outpatients, clinics and home care are the present catch-words

in hospital discharge planning.

The upshot of these pressures places the futility debate in a new light. On one hand, the physician has a moral obligation to do what is best for his patient. On the other, given the limited resources, it is justifiable to limit treatments that are expensive and offer minimal benefit. Lantos writes,

> Prior to prospective payment, doctors were apparently untroubled by patients' demands for futile treatments. Instead of arguing that it was unethical to provide such treatments, they generally argued that loyalty to their patients required that every potentially beneficial treatment be offered and one could not put a price on life, that even if the chance of success was only one in a million, doctors would still be ethically obligated to provide it. When reimbursement incentives changed so that doctors began to lose money instead of making money in providing such treatments, doctors suddenly discovered an ancient ethical obligation to refrain from providing such treatments.[22]

Lantos and Murphy seem to have struck an important chord in their link between economic conditions and futility. The most difficult point of contention and struggle even within simple medical procedures is cost containment from patient testing to operating room procedures. Questions arise when injecting a dye to observe arteries. Do we use the less expensive dye or the more expensive? Which pacemaker is installed, the expensive one or the cheaper? Which medical nutrition is offered, the better or the "regular one" which costs less? Patients do not realize that the resource allocation can be invoked in many contexts, not only in life-threatening situations. It can simply involve any procedure or medication which has been decided as not necessary or described as unnecessary in the situation.[23] The danger is that a mind set concerned with rationing and lowering costs will spill over into the futility debate.

Bruce Zawacki on Futility

Zawacki describes the futility debate as a knot. He says, "apparently, continued controversy has transformed the futility debate into a contemporary Gordian Knot made larger, tighter, more intractable and more fundamentally irresolvable the longer it has been argued".[24] He endeavours to disentangle this knot through the environment of bedside medical practice which could encourage interpersonal ethical dialogue between the parties involved.

> Now, perhaps, it is appropriate to recall that although futility may be the essential focus of the conflict between the paternal and informed consent paradigms that we have been describing, existentially, bedside conflicts are not between paradigms, but between persons.... Persons whose lives have become locked in small, more particular knots of interpersonal conflict... Real doctors and real patients are not mutant, stick-figure caricatures missing heads or bodies. Both are made of flesh and blood, mind and body, and affect and intellect; both are deliberate and impulsive, fearful and loving, ignorant and knowledgeable.[25]

Zawacki's approach is to untie the knot from the inside using what he calls a "subjective individual, collaborative model" idea wherein both patient and physician express their feelings, fears and hopes in order to first establish a relationship before making any final decision.

> In this approach, disclosure should only be the beginning of conversation. It should initiate neither coercive *medical* paternal discussion, nor coercive *judicial* consent/control discussion, but rather non-coercive ethical dialogue that seeks partnership and collaboration by communicating first to understand and then to be understood; by asking questions, challenging and seeking to establish a trusting collaborative synergistic *win-win* rather than a *win-lose* position of domination.[26]

A valuable method to begin this relationship is to invite family members to join

the care delivery team, preferably daily or at least every other day at the bedside teaching rounds in the ICU. Optimally, after some time, the patient may be more alert and the family more sophisticated about the diagnosis, prognosis, alternatives, and interventions which could be discussed with patient and family. Zawacki gives an example.

> For example, because a patient (a wealthy husband and father) had asked for it on admission, his family insisted later that *everything be done* even though he was septic with a very large burn and had failure of multiple organs despite maximal therapy. Quoting him, if cardiac arrest occurred, they wanted CPR to be *"repeated until my body is cold"*. Only after prolonged daily discussion did the family convince me and other caregivers that the request was reasonable: the patient was a self-made man who *regularly did the impossible* and to do less would have dishonoured his life of reaching for impossible dreams and achieving them. He was subjected to CPR until his feet (the only unbandaged portions of his body) were pronounced cold by his wife. From follow-up several years later, we learned that the family members felt that this collaborative decision was the most important source of strength and integrity in facing life after the patient's death.[27]

Zawacki develops a collaborative model and suggests three steps to be taken before final disclosure. Physician and patient/surrogate: a) appreciate alternatives; b) balance the burden and benefits; c) commit to a care plan; and finally, d) the physicians disclose the medical futility of the situation.

Zawacki also discusses the role of the HEC (hospital ethics committee) and warns that such committees can become paternal or judicial using a "funnel" model of discourse. They may refer to medical or legal consultants and offer non-binding recommendations that would be difficult to refuse. He suggests that the HEC develop a counselling or educational model and present themselves as counsellors and moderators for adult dialogue.

Zawacki believes that there are assumptions, personal beliefs and attitudes behind

the participants in the futility debate which have to be aired and clarified. He lists a whole series of questions for the physician and families about their personal beliefs on disease, pain, dying, death, abandonment, religious beliefs and support systems.

Stuart J. Youngner on Futility

Youngner says the futility debate has neglected some important issues. Cases describing the paternal/autonomy conflict

> "are but snapshots in time and give little perspective of the historical, social, and personal context in which these situations arise and that motivate people to demand interventions when competent and compassionate health professionals would say no. Taking better account of these motivations will not tell us where to draw the line. Nor does understanding motivation mean caving-in to unreasonable demands. Such understanding does, however, offer the opportunity to provide optimum care for dying patients and their families and to promote shared decision-making. Understanding motivations may reveal ways in which physicians and health care institutions can improve the way they deliver care to dying patients and their families."[28]

Youngner claims that health care professionals fail to set treatment goals early enough. Physicians often focus on treatment intervention rather than the goals they hope to achieve. He offers an example of the wife of an otherwise healthy 80-year-old man admitted into a cardiac unit with chest pain. The doctor-in-charge asked her, "If your husband's heart stops beating, do you want us to try to start it up again?". The patient's wife was incensed. "Of course I want them to start it again", she told me. "What on earth were they thinking?" It is least helpful when families are approached with the question, "Do you want us to do everything?"[29] The question is almost incredible and

shocking unless there has been a certain dialogue and understanding of the whole situation. There had to be a process of shared decision-making where goals were communicated clearly between both parties. Youngner says that many physicians have difficulty with this task. Talking to patients and families about death and dying requires interpersonal skills as well as a sense of timing. It is often avoided or postponed to the very end when last minute decisions are made.

Associated with this failure in communication with the patient and family is the illusion of control, the burden of responsibility where physicians have difficulty in admitting that they have lost control of the medical situation even when the patient and family are ready to give up.

> As one physician confided in me after I had given a lecture about futility *Why won't we give up? We are scared. Not just scared of getting sued. We are scared of being wrong.* The illusion of control, feelings of guilt... In contrast to the paradigm cases presented in the futility literature, the physician-in-charge is often the last one willing to pull back. Should we expect more from the families?[30]

Ignorance, especially on the part of the family, is another reason why conflict develops between physicians and families. In the case of our 80-year-old patient's wife, she may have had no idea of what the procedures of cardio-pulmonary resuscitation do to the patient and the expected outcome if he arrested. Again, this can be attributed to a lack of communication and is an example of miscommunication between staff and family. Youngner quotes Donald Murphy, a medical director of a nursing home, who encouraged discussions on death and dying with patients and family, and "avoided using misleading euphemisms like, *Would you want us to do everything to save your life if your heart stopped beating?*".[31] When he provided patients and families with accurate

descriptions of their medical conditions, poor prognoses, and unpleasant realities of dying and critical care environments, they uniformly (23/24 patients and all but one relative of an incompetent patient) rejected resuscitation... By taking this direct approach, Murphy truly empowered his patients and their families and avoided the "gun fight at OK Corral".[32]

Confusion is another element which encourages families to demand futile treatment. This is caused by contradictory information given by various physicians and health care professionals who have different views on the situation. For instance, oncologists who have initiated treatments with patients and family consent are generally more aggressive on treatment modalities than their counterparts in the ICU. Confusion is also aggravated by the "multi-consultant phenomenon". In critical care, specialists are often brought in to the case and each one is watching a different area of care. When the family meets with each consultant, they report on the specific area that they are watching and fail to convey how the patient as a whole is faring.

Mistrust is sometimes inherent in the family-physician relationship especially around poor and minority groups. There are subtle but persistent forms of racism and discrimination which are especially evident in the United States where very few of the poor and minority groups have adequate care in the health care system. Youngner writes, "In my own experience, poor and minority patients/families are less sympathetic to notions of futility. It is no wonder that they want everything done at one of the few times that they are able to demand anything at all."[33] Further, some physicians have not been forthright with families and have even used deception at various times.

Finally, Youngner discusses hope and the frontier mentality which has been developed and nurtured within the last thirty years. Patients and families are overwhelmed with our new technology, believing that today we can really offer hope to the families and patients who are extremely ill and even dying. Our capacity to face reality is difficult, standing in front of the high tech ICU bed. Youngner says,

> "hope and critical care technology have too often proved an unfortunate mix, especially in a society with a frontier mentality and litigious bent. When therapeutic intervention becomes a technological imperative and hope turns into pathological denial, patients and their families suffer unnecessarily. The concept of futility may provide a much needed corrective, but will better fulfil its promise if those applying it also give attention to the social, psychological, and institutional problems fostered demands for futile care in the first place. Just saying *no* is not enough."[34]

To summarize, I have discussed the views of eight different ethicists and their approaches to resolving the futility issue. Schneiderman and Brody emphasize the role of the physician and the importance of the integrity of the profession. Their major argument is that medicine is a specific science and art with its own internal rules, which form the basis of a doctor/patient relationship. It is essential that physicians do not break trust with the patient by encouraging false hope and providing ineffective treatment.

Veatch and Lindemann-Nelson favour the patient and family, although for different reasons. Veatch questions whether physicians have a right to be involved in determining futility. This judgment transcends the expertise of the medical profession and enters into the realm of moral philosophy and theories of the good. Nelson emphasizes family relationships which construct human selves. Physicians tap into these relationships but it is only the family which can understand them, shape values and

accommodate our most basic needs.

Lantos refers to an understanding of financial motivations behind the futility debate. Murphy argues that it is mainly a matter of economics and that it is difficult to separate the concept of futility from rationing issues when there are societal forces which impinge on the physician's point of view throughout treatment. Most of these ethicists and others, including Schneiderman, Brody, Ronald Cranford[35], Linda White-Johnson[36], and Robert D. Truog[37], also emphasize the role society must play in defining terms, rules, and guidelines.

Finally, Zawacki and Youngner stress the importance of communication within the framework of the futility debate. This is not to say that others do not place importance upon communication, but Zawacki and Youngner offer the beginnings of a model. Youngner also emphasizes the importance of communication as an ethic of prevention. Requests for futile care can be iatrogenic in nature, stemming from a physician's failure to discuss achievable goals with the family. There are also issues in understanding motivations of physicians and families which contribute to the debate, such as family ignorance, confusion and the physician's difficulty in talking about death and dying in a culture which has nurtured the frontier mentality in futile situations.

Critique of the Schneiderman and Brody Approach

As noted above, Schneiderman and Brody favour the rights of the physician and are concerned about the integrity of the profession. At first, Schneiderman et al took

the extreme view that there were no obligations upon the physician to enter into any dialogue with the patient or family in the medically futile situation. They have since softened their position leaving the doctor to inform the patient and family but not to make the mistake of creating any dialogue which would allow the patient to decide on a treatment plan. In essence, the patient has no right to expect any information from the physician unless the physician decides to share some information.

Schneiderman has had his critics, notably Robert D. Truog et al and John D. Lantos et al.[38] Truog et al argue that short-term survival versus long-term survival is a value judgment. Patients or family members may value the additional hours differently than physicians. There is a subjective component to consider in quality of life. The closest to a value free understanding of futility would be the notion of physiological futility. But even this is problematic because if the patient can be kept alive with mechanical ventilation and oxygenation, then families may accept this as a goal worth pursuing in the hope of a miracle. Tomlinson and Brody agree that all judgments about futile interventions are value judgments. They write, "antibiotics (for a viral cold) will not cure the cold but they will satisfy the patient... so antibiotics are not absolutely useless... maybe antibiotics will knock out a sub-clinical bacterial infection that otherwise would have fulminated out of control". Also: "maybe a computerized topographic scan will detect a wholly unexpected tumour in a patient with (or without) a tension headache".[39] However, the authors also warn us that physicians, no less than patients, also have a right to make and live by value judgments: "a cardiac surgeon cannot be obligated to honour an angina patient's demand for bypass surgery when the surgeon has

determined that the patient is a poor surgical risk who is more likely to die on the operating table than to have his angina relieved... a principle that denied the physician any power to act on his/her professional values, rather than the patient's, would leave the physician powerless to refuse to perform actions that harm patients... the best safeguard against professional arrogance and arbitrariness is not patient arbitrariness but rather an effective social dialogue."[40]

Truog et al also questioned Schneiderman's quantitative approach.

> Futility is almost always a matter of probability... but what statistical cut-off point should be chosen as the threshold for determining futility?... Schneiderman and colleagues recently argued that a treatment should be considered futile when 100 consecutive patients do not respond to it. But how similar must the patients be? Necessitating the efficacy of mechanical ventilation to treat pneumonia, for example, is it sufficient to simply recall the 100 most recent patients who received artificial ventilation for pneumonia? Or must this group be stratified according to age, etiological organism, or co-existing illness? Clearly, many of these factors will make an important difference.[41]

The danger is that a mind set concerned with saving money will bias the futility debate.

There are other critiques of Schneiderman et al. The logistics in keeping track of 100 patients; does this have to be in a single hospital? Studies show that doctors differ in their conception of futility, especially physicians from different disciplines such as cardiologists, pulmonary specialists, oncologists, etc. What happens if there is less than 1% shown to recover? From my personal experience, the concept of futility can be dangerous as it can be used against the poor and those who have no family or caring friends. What about families and patients who are willing to experiment? Are they eliminated? Finally, atheists say that those of us who are superstitious or that go to

church or synagogue are involved in a futile waste of time. We all do things which science would say is futile. What to some is futile is an important belief to others.

Another critic of Schneiderman and Brody is Susan B. Rubin. Rubin devotes two chapters in her book[42] to questioning the approach of any unilateral decision by the physician in both quantitative and qualitative futility. From the qualitative view, she uses the generalization of expertise argument which is similar to Veatch's view. She writes,

> Physicians, qua physicians, cannot claim to be experts in the values that should and do govern medical decision-making by patients. Physicians can only articulate what is medically possible, not what is reasonably worth pursuing for a particular patient.[43]

In validating this approach, Rubin points to the Karen Quinlan case where the physicians were reluctant to remove all life-support apparatus from Ms. Quinlan, although she was in a PVS state. The Supreme Court of New Jersey decided for her parents, as surrogates, to discontinue the ventilation in the belief that the decision to remove her from the respirator was not a medical decision, but also a moral one in which the parents' rights were affirmed.

The argument from the view of patient autonomy is that granting physicians the right to make unilateral decisions on behalf of their patients would be a return to pure paternalism, a step backwards in health care in our way of life which advocates respect of persons. Here Rubin writes,

> One of the most disturbing features of the popular proposals that advocate physician refusal to offer, provide, or continue treatments on the ground of evaluating futility is that they accept and promote the legitimacy of physician unilateral decision-making. By definition, *unilateral* implies that patients, even competent patients with the requisite decision-making capacity, have no opportunity to participate meaningfully in discussions with the physicians about their care.[44]

From our experience, such a unilateral approach would signal the beginning of the end of an already fragile doctor/patient relationship. This complete disregard of informed consent smacks of a need for the physician's regaining of power lost approximately thirty years ago when patient autonomy came to the fore.

Physiological futility, however, is much more difficult to dispute. At this point, the physician may argue that his decisions are value-free and that he is only concerned with the facts in the case. Rubin, again, contends with this position claiming that physiological futility is also governed by the physician's values. Philosophically, she questions our capacity to obtain knowledge and truth even as we use scientific methods. Like Truog et al, she argues that there is an element of uncertainty because medical interventions can differ, depending upon the capacities of each patient, biochemically, physiologically, psychologically, and spiritually. It is precisely this uncertainty which makes medicine not just a science but also an art. Thus, Rubin writes:

> "judgments of physiological futility necessarily have at their base an evaluative judgment, if only a judgment about the degree of certainty one finds acceptable and unacceptable. And again, the question is whose value should be determinative in selecting acceptable degrees of certainty?"[45]

Closely associated with uncertainty is the problem of mistakes. An article in the *National Post* reported that 20,000 Canadians die each year due to medical errors.[46] The article claimed that tens of thousands more are disabled by drug overdoses, surgical errors, or failure to treat injuries. An American survey revealed that up to 98,000 people are killed each year through medical errors.[47] The figures from both countries do not include the giving of wrong medication, wrong diagnosis, and just the fact that

thousands more are left without a definite diagnosis. On rounds, I often hear, "Rabbi, can you help me. I am in the hospital for two weeks and they still don't know what's wrong with me." Some American hospitals make it mandatory to report medical mistakes. In Canada, it is not mandatory to report even adverse reactions to drugs. Rubin sums it up,

> The range of criticisms... from the problems of objectivity, value neutrality, method, interpretation, and uncertainty, to mistakes seriously undercut the popular treatment of physiologic futility as a sufficient ground for physician unilateral decision-making. I contend that, in light of these problems, the practice of privileging or making an exception of physiologic futility and using it to justify physician unilateral decision-making ultimately becomes indefensible.[48]

Critique of the Lantos / Murphy Approach

Murphy, as we have seen, is outspoken in the relationship between economics and futility decisions. For Lantos, as well, it is a serious consideration. In fact, within all Canadian hospitals there are constant memorandums and warnings to physicians and residents to try and reduce costs through refraining from unnecessary tests, using less expensive drugs and early discharge. This reality is a fact of life in all Canadian medical institutions.

There are, however, arguments that one could apply against the Lantos/Murphy approach. First, I am uncomfortable with the belief that physicians unilaterally have the right, albeit because of government pressure, to act as health care rationers. Physicians are there to cure, not to ration treatment. It would be more palatable if there were a

public consensus or legal guidelines set by governments coming from without the medical profession which would set the standards. Perhaps, at that point, patients and families would have the opportunity to opt for private insurance. The present situation places us at the mercy of a doctor's decision.

Second, if physicians are left to decide which treatment is cost-worthy or not, then we are concerned about allowing ethically irrelevant factors such as the social worth of the patient to enter the equation. The poor, the vulnerable and powerless may be left out and suffering from the effects of such rationing. There must be clear standards of what is considered cost-worthy or not.

A third problem is that a conflict of interest is created between physician and patient. If the physicians are the official gatekeepers to insure that money is well spent, they will lose the patient's trust, in that the patient's well-being is not their first concern. This is in direct contrast to Lantos' emphasis on the development of a doctor/patient relationship based on trust. When the doctor suggests early discharge or palliative care, the family may suspect the physician's motivation. The whole concept of working for the patient's best interest now engenders many doubts.

In conclusion, the problem is not one that can be shunted to the side in the name of ethics. Ethics are not written in stone and even ethical theories, as such, could change. Until the problems in solving health care shortages are resolved, the economics issue will always rear its head in the context of futility.

Critique of Veatch and Lindemann's Approach

There are major differences in Lindemann and Veatch. Lindemann favours the rights of the patient and family. Essentially, he argues that the patient is part and parcel of the family and the family knows him/her best. Veatch, too, favours the family, but from a different vantage point. He questions the physician's knowledge and right in making moral decisions. Veatch argues that the physician's knowledge in medicine does not make him/her an expert in life and death decisions, including quality of life. In either case, both favour the family and question the role of the physician in making futility judgements, other than stating the medical facts.

Their point has some inherent weaknesses. First, it is difficult to restrict physicians to facts and not judgements. For the physician, saving a life is a moral practice. This, in essence, is their trade. If the family believes they have the right to ask for aggressive treatment when the physician considers the treatment inappropriate, the physician may counter, "I am not obligated to follow your wishes. I, too, have rights. You cannot force me to practice an inappropriate procedure." In other words, the argument of the patient's autonomy only gives the right to non-interference. It cannot force the physician to do what the family insists. In addition, it is no more justified for a physician to impose his will on a patient than for a patient to impose his will upon the physician.

Brody, in his argument for the physician's professional integrity, reasons that if the physician has no authority and control, the profession is reduced to being mere

technicians subject to the whim of every family with rational or irrational requests. Rubin takes this a step further. She argues,

> Medicine, the argument goes, is not a value-free enterprise. The fact that it is founded on at least two essential and explicitly stated defining values: the commitment to do good and the commitment to avoid harm. These values encapsulated in the principles of beneficence and non-maleficence, form the only basis for the obligation of a physician qua-physician to enter into a therapeutic relationship with a patient. A physician qua-physician would not be justified in offering treatments to a patient if the provision of the treatments would violate these foundational principles.[49]

It may also be that Veatch's position is politically-oriented. He undermines the role and political strength of the medical profession in stressing patients' rights and the theory of the whole good. He stereotypes the physician almost as a narrow-minded individual. The patient-doctor relationship almost appears adversarial at times. These views may be excessive. Many patients and families look to the physician's opinions in futile situations. Robert Baker, in his criticism of Veatch, is also concerned about the patient's concept of self-control versus self-fulfilment which may be destructive."[50]

Nelson, too, seems to favour the family, even in unrealistic circumstances. He places the onus on physicians to understand the family. Perhaps this is an extreme. Court cases have gone both ways. The best way is, perhaps, to have more dialogue.

Critique of Zawacki and Youngner

Both Zawacki and Youngner emphasize the importance of communication with the family. Youngner emphasizes that meeting with patients and families should include

shared decisions by setting early goals, being clear on the diagnosis and treatment plan, and being certain that the family understands what is happening to the patient as a whole and not being misled with fragmented information. Zawacki seems more bent on the development of the physician/family relationship. He asks for an ethical dialogue, one that is non-coercive or paternalistic and does not even appear that the physician is seeking consent. It should be a collaborative partnership model which would invite family members to join the health delivery team and help in the decision process. He insists on being completely open with the family to the extent to admitting personal vulnerability on the part of the team. He even warns against the use of Hospital Ethics Committees (HEC) which may be used as funnels to reinforce hospital and physician policies.

From my experience, Zawacki has most accurately described the HECs of most hospitals. They primarily use the "funnel" model of discourse. They tend to see themselves as objective, truth discerners, truth providers and not truth seekers. They usually operate by listening to the complaint, advising the physicians in charge and trying to find a compromise if possible which usually irritates both family and physician. On the other hand, they cannot be censured. Time pressure does not lend itself to the counselling model. Zawacki refers to continuing maximal therapy for a few days so that the family can be helped through a denial phase of grief. Do we have time for such dialogue when ICU beds are at a premium and the ICU physicians and nurses feel that "there is just no point in prolonging death"? However, Zawacki's suggestion of having the families establish an early pattern of cooperation and trust by inviting them to rounds is an excellent suggestion. These rounds traditionally have, and still can, establish as

normative telling the truth, openly examining every issue in excruciating honest detail, revising opinions with new information, labelling no question as too elementary and virtually none as too sensitive, and stressing the importance of input from the entire team including the patient and family in day-to-day decision-making.[51]

I am not certain about Zawacki's plea for an expression of internal vulnerability. As a surgeon, Zawacki is perhaps honest in his approach. However, in most cases, a surgeon shows an air of confidence and assurance in his dealings with patient and family. This is what patients want to hear. They often ask me, "Rabbi, is he a good surgeon?" when I see them before the operation.

A final note concerns the collaborative and counselling models, which may be idealistic. It isn't easy. Often the physician and families suspect each other or one member of the family is religious or stubborn, which causes divisiveness. Sometimes the physicians are abrupt and have no time for "silly questions". They feel that they are there to advise, not to listen or counsel. They also have to deal with fatigue, impatience, and miscommunications.

Youngner, too, does not offer any model in solving the communication problem. He explains that the physicians are aware of the problems and pitfalls but does not suggest any process for how communication should take place. He has also left out the issue of abandonment. When physicians apply the futility argument, abandonment usually takes place unless palliative care takes over. This sense of abandonment of patients and families is, perhaps, associated with the physician's loss of control and burden of responsibility. The physician can no more help the patient. His mandate is

to heal. It is not that he doesn't care, but this is not his expertise.[52]

Summary

In summary, I have tried to examine some of the problems in defining medical futility, recognizing the forces which impinge on any definite approach. I have also presented the views of eight ethicists who have analyzed the problem. I highlighted that they constitute four different schools of thought. Schneiderman and Howard Brody accentuate the problem as an erosion of physician rights which has to be rectified. Robert Veatch and James Lindemann question these rights and opt for a stronger view of patient and family autonomy in order to manage the issues. Donald Murphy and John Lantos are concerned with rising medical costs and resource allocation. They do not see a resolution of the futility debate unless we take into account a fair and just consideration for society as a whole including access to a just health care system. Bruce Zawacki and Stuart Youngner emphasize the communication process as the only way to diffuse any difficulties or confrontation between the stakeholders of the debate.

I tend to agree with Zawacki and Youngner. The field of medicine contains more than "rights", "duties", or "definitions". It is more than a science. There is a moral and ethical aspect of medicine which is part of the art of medicine. This primarily involves relationships and communication among and between physicians, patients and families. This is where Zawacki and Youngner differred from their colleagues in their presentations at the American Geriatric Society Congress.

I, however, will expand on Zawacki and Youngner. Both wrote in general terms, explaining what they would like to see in a physician/family relationship. Both do not discuss the mechanics of the communication - how it is to be accomplished. They have not taken into account the Canadian system which demands a quick response because of extremely busy physicians working within a framework of intense pressure, including bed shortages, budget cuts and demands of often unreasonable families. Zawacki talks about a questionnaire which would examine beliefs and feelings of physicians regarding futility and death. In my estimation, it is unrealistic. It may have certain advantages, but it would take days to decipher and we would probably have to add a psychologist or psychiatrist to address the issues. Youngner, too, is concerned about the physician who has problems in losing his patience, in being wronged, in losing control. He offers no solution.

In contrast, my model will address these problems. I will propose a set of guidelines which will assist those working with families within the framework of the Canadian health care system. I will propose standards for what is good communication and adapt these standards to this situation. But first, I turn to the physicians, their training in ethics, their relationship to a changing health care system, and then my questionnaires to physicians and families -in regard to communication and futility.

Notes

1. The medical literature, as mentioned in the introduction, has very little to say about the role of the family. At best, principles of doctor/patient confidentiality would only include families when the patient is incompetent. The doctor's allegiance is to the patient - no one else. The Jewish General Hospital's Critical Intervention Policy reads, "sharing of information should only be done with the patient's agreement". The policy also states, "Resuscitation will not be undertaken in those instances where there is no chance of effecting sustained and functional reversal of the critical event. This decision will be made and documented by the attending physician and requires a documented second medical opinion." "Although patients must be apprised of the therapeutic plan, they need not be informed of all measures that are to be withheld on grounds of futility." To my knowledge, this policy is not different from other area hospitals. (See Appendix A: Jewish General Hospital Critical Intervention Policies, pps. 3-5.)

2. I will discuss this more thoroughly in Chapter IV.

3. Some hospitals supply kosher frozen airline or catered food which is often disliked. Special diet menus are usually unavailable but, often, the "food" argument is just part of an excuse.

4. This exchange does not happen very often, but it does happen, in part, where second and third opinions are requested, palliative care declined and further aggressive treatment is refused. And even when families do agree with physicians, there are lingering doubts, as we shall see in Chapter 3.

5. Although the term "quality of life" is not new, it becomes very complicated. We live in a complex era hampered with pressures that confuse and paralyze the issues. Overworked physicians, nurses, technicians and support staff, overcrowded hospitals with bed shortages indirectly affect how we look at our elderly patients' quality of life. Added to this is the family who wants everything possible done to save the patient. They argue in terms of sanctity of life, insisting that any form of human existence has intrinsic worth. The overwhelmed physician confronted with this family may find the argument illogical or even absurd. We then have a polarization of thought and poor communication as the physician and family may be talking past each other and not to one another.

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CHAPTER III

THE PHYSICIANS' SETTING

Introduction

The purpose of this Chapter is two-fold. First, notwithstanding the growing world-wide attention to medical ethics, I will show that there is a lack of clarity on the role of ethics in our medical schools and institutions. At best, ethics is brought forward in a post-facto manner where physicians, families and ethics committees scramble to find a solution to problems they confront. Second, because ethics has been relegated to a subordinate position, difficulties in problem-solving, conflict resolution and communication in general have become more evident. Just at the moment when good communication could be a vehicle to solve problems, although physicians believe they communicate well, many families believe the exact opposite.

I begin the Chapter examining the medical students' education in ethics, how they view medical futility and the effect it has upon physician/family communication. My hypothesis is that ethics is not an important component in formal medical education. Our medical schools emphasize the curing aspects of medicine, not the ingredients of caring. Within the framework of a rapidly growing discipline which includes an enormous amount of newer knowledge concerning disease and treatment, medical schools are

forced to concentrate on the areas which give prominence to the hard medical facts and how to cure the patient as quickly as possible. Added to these pressures are the technological and pharmaceutical advances which leave very little room for palliative care in medical education. The upshot of these demands is that the ethics of doctor/patient and family relationships and communication has a subordinate position in the curriculum of medical institutions. They know of its importance, but in terms of priorities, they struggle to find the time to place ethics in their teaching program.

The second part of the Chapter deals with physician, government and hospital administration. I will show how the present medical system is making the doctor/patient/family relationship extremely difficult. The result is that ethics is placed on the back burner of priorities and all ethical hospital protocols, including policies and procedures in critical intervention, are put into departmental manuals to be used only in extremely difficult cases. Thus, the major players in the end of life decision process are unequipped to handle conflict and communication tends to break down.

The Student Physicians' Education in Ethics

Teaching ethics is a strange activity, especially among older physicians. After our hospital had acquired a clinical ethicist on staff, a surgeon expressed bitterly, "It's all a waste of money. Nobody has to teach me how to be ethical. Furthermore, ethics is something that cannot be taught. One has to have it within him." Perhaps his attitude was due to strong self reliance, individual conscience, experience of many years and a

belief that ethics belongs to the doctor in charge of the patient. There also may be a suspicion of an outsider, an ethicist knowledgeable in philosophy or law dabbling in medical decisions which are not part of the ethicist's expertise.

The above concerns were also voiced by Edmund D. Pellegrino in his discussion of some of the questions which constantly arise in teaching medical ethics. The questions include, "Can ethics be taught?" "What does the professional ethicist contribute?". Pellegrino answers the questions, but admits "some of these questions result from misunderstandings and some reflect the *two-culture* mentality which divides the world into *hard* and *soft* knowledge... None are trivial and none can be ignored or treated condescendingly."[1] These misunderstandings continue to haunt us. As we shall see from our research, students, residents and physicians still struggle with the necessity for teaching ethics in our medical communities.

Notwithstanding these concerns, attitudes are slowly changing. The medical profession has been inundated with many ethical issues almost unheard of 25 years ago. First, patients and families now play a greater role in the decision process. Physicians are faced with a more knowledgeable patient who suddenly asks for more information before deciding on how to proceed. The law also requires informed consent where physicians must explain all the pros and cons of any medical procedure. Thus, students find themselves on the defensive, having to answer a host of questions fringing on ethical issues to a more informed patient population.

Second, many newer technical capabilities pose ethical questions in all medical areas from genetics to end of life issues. There are newer legal issues, powerful new

drugs, transplantation of multiple organs, artificial hearts, invitro fertilization, euthanasia, genetic engineering and screening and issues in confidentiality - especially with HIV patients. In addition to these there are the regular medical issues, pain control, quality of life, rights and duties of physicians, defective newborns, rights of children and psychiatric patients, foregoing life-support, evaluating decision-making capacity, and a host of others which are faced daily in the hospital.

Third, we now have a complex group of providers such as government and hospital administration. This is similar to the private insurers and managed care in the United States which have brought economic concerns that have profound impact on our future physicians. Vladmir Dzadik describes situations[2] where patients are waiting up to a year for by-pass surgery, cancer patients for radiotherapy and eldery patients for hip replacements.

> It is at this juncture that medicine meets government. It is at this juncture that ethical decision-making by physicians regarding the welfare of his or her patients meets government policies which are, at an ever increasing rate, causing a rationing of health care. On one hand the resident physician is learning specialized skills and using new technology and yet on the other hand, he or she is being told that these skills and this technology are too expensive and their use must be therefore limited. We are faced with an ethical dilemma....
>
> No doubt we have an ethical responsibility to treat our patients in the most efficient manner possible using only those resources that are essential for making an accurate diagnosis and for providing appropriate effective therapy. How far though, should we, as ethical physicians, stretch the principles of distributive justice? Does the common good, measured in fiscal terms, prevail over the good of the individual, measured in terms of health and life? Or is it that the measure of the common good is not the right one?[3]

Dzadik's questions are at the heart of many ethical issues. The dilemma is brought forth to emphasize the quandary medical students and residents face when they

are taught to do everything possible for the patient while finding their hands tied due to scarce resources.

The pressing question now is how far have we progressed in medical ethics education? How do we regard the teaching of ethics to medical students and what methodologies are used? There have been a few surveys of the medical schools in Canada which I will describe. I will not go into the results for each question on the survey, but only share a summary of their results as seen by the researchers.

In 1984, John R. Williams surveyed the 16 Canadian medical schools, inquiring from each the status of teaching biomedical ethics to the undergraduate students. He writes.

> Although there are far more students taking biomedical ethics courses and philosophy, religious studies and theology departments than in medical schools... there is a widespread conviction among the teachers of these courses that medical students are the most important target of instruction in this field. At the same time, the instructors feel that, for the most part, present teaching efforts in biomedical ethics in medical schools are quite inadequate.[4]

In answer to his questionnaires, interviews and invited comments, it was felt that there was no real commitment from medical schools to teach biomedical ethics. Often the dean and administration were concerned with a tightly scheduled curriculum which was difficult to adjust. Further, questions arose about who should teach bioethics, the physician or the ethicist-philosopher.

In 1989, François Baylis and Jocelyne Downie[5] conducted a similar study. At that period, all the schools except Queen's University offered courses in bioethics. The average number of required hours was just under 23 for the four year period. The

schools generally had excellent course content focussing on euthanasia, withdrawal of life-sustaining treatments, new reproductive technologies, abortion, allocation of scarce resources, and transplantation. The authors write,

> Generally speaking, the course objectives identified by the schools seemed appropriate given the nature of the ethical problem that now confront physicians. However, they were overly ambitious given the limited number of hours allotted for medical ethics education. How could so much be achieved in so little time? This is not to suggest that the course objectives should be downgraded, but rather that more time should be made available for medical ethics education so that stated objectives can be realized.
>
> A critical question that this raises is whether the existing courses in medical ethics provided medical students with a real opportunity to develop an ethical framework for moral decision-making or whether they merely highlighted some of the more difficult ethical issues in contemporary health care.[6]

Only six of the schools included discussion of ethical theories and of the medical codes. Classes were taught in a classroom setting emphasizing case studies. There was also a significant disagreement among the schools about the place of philosophers and persons of training in religious studies or theology in the teaching of medical ethics.

In 1993, the University of British Columbia also surveyed the medical schools. All sixteen schools responded to the survey. At this time the mean course hours offered jumped to 72, although only about 40 hours were required for credit for the four year period. 93% of the lecturers were from disciplines outside medicine. The methodology and core content of the courses varied deeply across the spectrum. Formats included lectures, small group discussions, plenary sessions, videos, and role-playing. 31% of the schools required textbooks.[7]

From six personal interviews with students at our hospital, I have had similar

responses corroborating these findings. Describing the teaching of ethics at one of our major teaching hospitals in the first two years, the courses did not meet well with the students. They complained of a didactic approach in which little response came from the class. Third year students who started their rotation in hospital received no courses in medical ethics from the university. Fourth year students did have a well-received seminar in which case histories were presented. Evaluations were not a serious concern for the students. Short essay exams were given from the notes taken and were considered easy to handle. Evaluation in general was considered difficult because how does one know or measure what a student has accomplished in ethics or moral reasoning? Perhaps learning ethics was not attained from the courses but from the hospital rounds or other aspects of the training programs. All the students felt ethics is important. They believed the university was not serious enough in their approach. They did appreciate and understand the university's difficulty in finding room for the courses in a most complex, difficult and time-consuming curricula.

Some of the students brought up a side issue of student abuse. They felt that at one time or another they were verbally abused, intentionally neglected and received no feedback from clinicians and teachers who were unreasonable in their demands. Even the one-in-four evenings on call demanded 72 hours of constant work which, although not permitted by university standards, was expected in the Department of Surgery for third year students. Margittai et al report on the results of student abuse. "Educators and administrators should be concerned that the outcome of experiencing abuse during medical training seems to influence students' satisfaction with medicine as a career and

to play a role in their subsequent choice of speciality (with implications for the distribution of personnel, both under-represented specialities and in academic centres)."[8]

Students are also subject to mental abuse by patients and their peers who are competing for attention. In a study by H.K. Silver and A.D. Glicken[9] of a major American university, it was found that 46% of all respondents stated that they had been abused while in medical school. Eighty percent of the senior class reported abuse while 69% said that some episodes were of major importance and very upsetting. Sixteen percent said that it would always affect them. The abuse described included verbal, institutional, sexual, physical and intentional neglect. One may assume that pressures to succeed make it difficult to be concerned about ethics under these circumstances.

In my discussions about in-hospital ethics with third and fourth year students, they expressed reluctance to interfere with the physician's patients and family in ethical situations. "It's not our business. It's the physician's responsibility and that's his/her style. We won't mix in. Besides, we probably would get hammered." Further, students are actually uncertain in their role and it is difficult for them to speak up. They will usually answer to please their staff person teacher in order to ensure their position rather than to take a moral stance. In a way, this is no different than most social groups who wish to keep an equilibrium, although it may be not morally correct.

In a paper delivered at a conference on medical ethics, Frederick Lowy describes an evolution in the teaching of medicine which has changed the approach of the personal virtue-laden ethical physician to the impersonal value-free non-interfering doctor. Some of the reasons Lowy describes we have shown above, including the physician's difficulty

in handling patient autonomy and the vast changes in technology. He also refers to a health care system which has provided physicians from a "variety of ethnic, cultural, linguistic and religious backgrounds, and most important, various and sometimes conflicting values and expectations."[10]

Today's physician-teacher is usually a medical specialist who emphasizes the newer technologies and methods of cure, which by their own merit have caused conflict, raised dilemmas and newer fundamental moral questions. Thus, the socializing of medical students into the profession is in conflict with any traditional model of the physician's role. Lowy asks,

> "What, then, is the appropriate stance of the medical professor at the close of this century who wishes to teach and practice ethically? My prescription is as follows... the ethical professor of medicine must not be such a value-neutral medical scientist... Today more than ever - in the face of ethical pluralism and our huge technological potential - patients and their families need a caring, beneficent, emotionally involved guide who does not shrink from moral complexity. The remarkable scientific progress during the twentieth century has not eliminated the need for such a guide. The contrary is true."[11]

> "The person who is ill and who seeks help needs neither an authoritarian doctor who imposes decisions that disregard his/her values nor an emotionally or morally disengaged technologist. What the patient does need is a professional partner who will guide decisions to the extent the patient - appropriately informed - wishes. The physician partner will not shrink from revealing his/her own relevant values but will only be guided by the uncoerced choices that the patient makes... What I am prescribing is a reversal of the pendulum swing that gained momentum during the half century in order to restore the priority of the physician healer for whom interpersonal sensitivity and traditional virtues are again an important means to the therapeutic end."[12]

Lowy may be right. But how do we do it? How do we make the pendulum move back? How does one become a traditional role model physician in the twenty-first

century? Our whole society has become impersonal, value-free and non-interfering. Can we expect our doctors, who have full schedules and offices filled with patients, to turn the clock back, making house calls, getting to know the family and not be concerned about the hours spent as in the traditional model? Todays patients, too, seek quick results, the easy and fast cure. I am also not certain that people would want the physician to be involved in their personal family lives.

A third approach to teaching medical ethics has been advocated by Hafferty and Franks[13]. They suggest that medical ethics is a hidden curriculum in the process of medical education. Ethics cannot be taught like a science course from without the medical curriculum. It is absorbed by the student only within the framework of his/her broadest medical studies. In the end, ethics becomes part of the physician/professional's identity.

At first glance, I was in complete accord with this concept of ethics as part of a hidden curriculum. The study of medicine has a powerful influence upon the student. It is a process of moral socialization. Virtue ethics is inherent to medicine as in every helping profession. The authors, however, seem to be bent on involving ethics in every medical act. They offer four recommendations. First, the faculty must be aware of the differences in the status, perception and culture of each student, not taking them for granted in the training. Second, there should be outside observers, social scientists who observe and address the training process. Third, all faculty, clinical and academic, should demonstrate the integration of ethical principles into everyday clinical situations. Finally, students should be made aware of the organizational level in ethical decision

processes. Decisions are made within an institution, not only on an individual basis.

These recommendations and comprehensive approaches, in my opinion, seem cumbersome and unrealistic. The authors admit "this is much easier said than done". "There is no quick fix." I would agree and add, once again, as medicine becomes more complex, government controlled with an aging population base, the student and resident become constricted to curing the patient and are less open to the institution of medical ethical guidelines and procedures. A senior resident explained, "In the real world, as one goes through medical training, one learns how to distance oneself from patients so as to manage their medical needs. Junior medical students deal with patients one-on-one, taking a biopsychosocial support approach to the patient and illness. Senior residents, on the other hand, who are responsible for running a ward with 36 patients, organizing tests, procedures and teaching, find their ability to interact with patients curtailed. Further, in order to cope with the emotional trauma of illness, residents develop a protective mechanism."[14] Thus, initiating the four broad recommendations of Hafferty et al, even within the framework of the hospital, would not seem feasible and would probably have a negative effect upon the student.

There may be, however, a simpler approach to teaching medical ethics which, on one hand, embraces the curriculum concept while, on the other, has only one recommendation - to simplify the educational process. I refer to Glenn McGee's phronesis approach[15] in teaching clinical medical ethics. The term "phronesis" originated in Aristotle's Nicomachean Ethics. He suggests a process of mentorship which, in the case of clinical medicine, would include medical ethics. McGee writes,

> Phronesis is a concept with several parts. First, it holds that the definition of an excellent person is tied to that person's every day behaviour as he or she practices in the community. The clinical ethicist or trained physician in clinical ethics is measured by how well he or she practices in that capacity. Thus, the crucial determinants of a physician's virtue are not his or her positions on abortion, euthanasia, or experimentation, but rather his or her ability on a daily basis to perform mundane tasks of a physician. Second, phronesis is an ability that must be acquired. This means that to become proficient, excellent and virtuous, we need a mentor. The key to picking up skills and acquiring virtue is watching as a teacher accomplishes similar struggles to those we will face. The mentor isn't just good at medicine, he or she is also good at being a doctor - in fact, the mentor (and this is the lynchpin to phronesis) defines good medicine for us. Whether we practice in clinical ethics or medicine, we are only as good as our teacher's work. Yet this presents problems. Just as I continue to struggle to explain what I do on rounds, my students in clinical ethics must struggle with me. Finally, phronesis requires what Aristotle calls "the discernment of the mean".
>
> For every characteristic a professional might possess, there are extremes. The person who has learned well from his or her teacher learns to find the mean between those extremes by observing the teacher as he or she moves through the clinic.[16]

McGee further says,

> Most importantly, phronesis demands that these cases be encountered in the clinic itself, rather than at a distance in a philosophy classroom. The immersion in real life clinical settings accompanied by a facilitating mentor, is indispensable for the developing skills of clinical ethics.[17]

I believe that this is the key. Teaching ethics is not there to make physicians comfortable in their position. Neither are we asked to be definitive in our ethical positions. A goal is to bring awareness of ethics in medical practice and improve proficiency in moral reasoning and communication. We encourage the deliberation emphasizing that there may not be a right or wrong in every case. It is the process that matters.

But most important is McGee's suggestion that phronesis demands that the cases

be encountered in the clinic itself. Perhaps university teachers would have to come into our hospitals to confront dying patients and families and the myriad of other ethical issues. But if that is what it takes, it should be seriously considered.

In conclusion, teaching medical ethics to student physicians is fraught with many problems. First, there are traditional beliefs that must be overcome, including biases from an older physician establishment claiming that doctors have nothing to learn from an ethicist. Further, there is a conviction that ethics cannot be taught from without, but is ingrained in the human psyche from early developmental processes. It has to be innate in the character of the medical student. Second, there are forces which impinge on the teaching of ethics, such as the medical model which stresses curing the patient as quickly as possible, keeping him/her out of the hospital system. Closely associated with the medical model are government and hospital administration policies which are concerned with economic issues that conflict with the importance of introducing an ethics curriculum in medical institutions. Third, the present methodology of teaching ethics is questionable. Does the time allotted by universities to a didactic teaching approach give the student enough of a background to handle the many conflicts of ethical issues? Further, are philosophers and ethicists the best teachers in the medical school, in a hospital setting, or should the teachers be physicians? And if physicians are the better teachers, who teaches the physicians to teach ethics? Perhaps a better approach would be a mentor-based, hidden curriculum approach in which students would learn from physician role models and have to handle ethical issues. The question still remains - Who teaches these mentors?

Finally, the study of ethics in general is not the cure-all for solving ethical issues. We are involved with people, humans who are often sensitive vulnerable or powerful. Michael Yeo writes,

> Ethicists have worked under the assumption that, qua ethicist, one can do no harm, that medical ethics can only be good. I submit, however, that medical ethics and the teaching of medical ethics has the same mixed potential for harm/benefit as does the **pharmakon** and as does medicine in general.[18]

Because of the above concerns, perhaps students have to be taught communication skills and that the learning of ethics involves good communication. As I have argued, ethics includes many important principles, but these have to be discussed, often taking much time and effort. In ethical decision-making, there are no fast rights or wrongs. Sometimes one has to compromise or mediate, but only through a process of communication. The problem is, once again, that ethics and communication is an issue neglected by the physician in the belief that it only takes simple common sense and ethics and communicative skills do not have to be taught. In the following section, I will be expanding on many of these issues.

The Resident and Medical Ethics

In my search for literature on teaching medical ethics to residents, I found publications of three symposiums which dwelt with post-graduate programs in Canada.[19] All underscored the need for remedial targets in order to enhance the importance of medical ethics within the framework of our hospitals. For just at a moment when one

may assume medical ethics begins to become important and urgent, the medical residents find themselves more isolated in dealing with ethical issues. This phenomenon does not stem from the lack of desire on the part of the residents to be knowledgeable in ethical issues. Nor does it come from a lack of initiative from the Royal College of Physicians and Surgeons of Canada. In its General Standards of Accreditation, the College suggests the organized teaching of biomedical ethics in residency programs and stipulates that the regular review of all residency programs must include an assessment of teaching in the program, including teaching in areas such as biomedical ethics.[20]

This was underscored with recent conversations I had with Dr. Eugene Bereza (Medical Ethicist at the Royal Victoria Hospital) and Dr. Edward Keyserlingk (Medical Ethicist at the Montreal General Hospital) who teach residents directly through programs at McGill and their affiliated hospitals. Both emphasized the realization on the part of medical associations to establish a curriculum for resident training in medical ethics. This is slowly being established by the universities in the form of Ethics Grand Rounds, regular scheduled seminars, ethics consultations and conferences in which actual cases are presented and through hospital ethics committees which share in the teaching program. The major problem, at the moment, evolves around the lack of competent teachers in medical ethics and the optional attendance on the part of the students. It is not yet taken serious enough by the students.

This problem, which most Canadian medical institutions share, is in contrast with many American hospitals that have teaching relationships with universities. These schools are intrinsically attached to the training programs in the post-graduate level. For

instance, a description of the teaching of medical ethics at Penn State College states:

> Our teaching of ethics for residents has two facets. The first uses familiar formats such as case conferences, grand rounds, morbidity and mortality conferences, attending physician rounds, and seminars that are part of the didactic component of the resident's curriculum... The second facet is an annual Spring retreat for residents and senior faculty from the various residency programs, usually including the residents who will serve as Chief Residents the following year. These overnight retreats permit a more searching exploration of ethical and humanistic dimensions of medical practice than is possible in the day-to-day hospital teaching. They are designed not only to explore the substantive issues in ethics and other humanities disciplines, but also to foster a sense of fellowship and rapport between residents and attending physicians as well as with us.[21]

This teaching model is but one of many where American hospitals are closely connected to the universities, often on one physical plane. It appears that at these universities the Humanities faculty is involved in the activities and structure of the medical centre of which it is a part.[22]

There are, however, problems and important considerations to examine in teaching medical ethics to residents. I have noticed this while doing interviews with residents in our hospital. These interviews developed out of my research as I tried to understand: a) the importance of medical ethics to our residents; b) their training; c) their attitudes towards ethical issues in general and futility in particular. Since I often use the hospital library for my research, there was no difficulty finding students and residents to interview. At first some were apprehensive. Others made appointments and didn't keep them. Finally, I had to assure them that our interviews would not be taped, they would be anonymous and confidential as to the sources. Perhaps my position as Director of Chaplaincy carried an element of intimidation and a possible concern that I would mention something to their superiors whom I know quite well.

My open-ended questionnaire involved five areas: 1) Do you know the hospital's critical intervention policy? 2) Do you ever lie to protect patient or family? 3) Do you have a role model and are you a role model for other students? 4) In cases of futility, whom do you talk to first; the patient or family? 5) When the family is in disagreement with you in futile situations, how do you respond?

In answer to the opening question, only one resident had heard of our hospital's critical intervention policy. He explained "I am a senior resident and sat on the Ethics Sub-Committee with the hospital ethicist in writing the policy." He wasn't surprised at the general response because "students and residents are very busy and although they are constantly involved with ethical issues, they tend to solve the issues using "common sense" or simply "go with the flow". Some residents explained that they just didn't know about the policy while others blamed the hospital for not publicising it enough. I mentioned that it was publicized and distributed to them upon entrance to the residency program. In fact, it was finished two years ago.

Concerning the question about lying to families and patients, this same senior resident offered this story.

> "I was working in the ICU when this young man was admitted in very serious condition and diagnosed as HIV positive. He knew he was going to die but had one request from the ICU. *Please do not tell my parents of my condition. Tell them anything, but not that I have AIDS.* The ICU went along with the young man. They lied to the parents until the end saying that they were not sure why he had this terrible infection and it was too late to treat it."

When I asked this young resident why the ICU would do such a thing, he answered, "Rabbi, it did bother me. Perhaps, I should have brought it to the Ethics

Committee. Sometimes you go along with the flow and don't ask questions, especially in the ICU with all the pressure they are under."

It is not my intention to dwell upon the philosophical dimensions behind the story. However, it does raise many ethical questions. Is it right to go along with the patient and lie to the family? Is it right to go along with the family and lie to the patient? Is there a difference between lying to the patient and lying to the family? And what constitutes a lie? Is the "white" lie permissible in order not to hurt feelings of families or patients? Many physicians would go along with this last suggestion while many would not. I believe both Judaism and Christianity agree that in certain instances, especially involving life and death decisions, one may bend the truth by not coming out straightforward but by skirting the situation. For instance, the ICU could have told the family, "His immune system has broken down. We can't be 100% certain of the cause, but the antibiotics are not working." And what about the quality of compassion in not being judgmental? Are ethics always etched in stone? These are some of the questions that residents and physicians may ask themselves in the futile situation.

When asked if they had role models, all agreed but had different role models depending upon the medical service they were going to specialize in. All the role models were physicians. This is in accord with Kinsella who writes,

> ... based on medical custom, one can predict that clinicians always will be the role models preferred by clinical trainees. Unfortunately, of course, this custom would currently be inappropriate for clinical ethics teaching in most centres in Canada, given that most clinicians themselves express the same educational deficiencies in medical ethics as their student disciples... What I also wish to convey, however, is that to successfully train future clinicians at the bedside, the teacher must always be seen by his or her students to be what they themselves wish to become, namely,

clinicians.[23]

This indeed presents a dilemma. How do we train clinicians to be knowledgeable in bioethics? It is one thing to have humanities, philosophy and principles of bioethics taught in under-graduate school. However, as students enter residency, they develop newer role models similar to their own aspirations which they would emulate.

Kinsella may be right. It may be an excellent idea if these physicians could be recruited from those who have retired from practice. The resident would then obtain the knowledge and the years of personal experience of practitioners in their field.

Regarding the question of whom to tell first, patient or family, the residents seemed quite sensitive to the issue. They were divided. Most felt it was the family who were first told, although, theoretically, it should have been the patient. All agreed that the patient had to know if he or she wants to know the truth. But they were uncomfortable in breaking the news to the patient. "Rabbi, most of our terminal patients know the truth but refuse to talk about it." "I haven't been trained on how to do this. It's difficult. How do you do it? Sometimes, even telling the family is difficult." The residents identified a strong unmet need in how to break bad news to the patient and it seems that the physicians in charge were having the same difficulty. This brings us back to Kinsella's argument that staff physicians have to be trained in ethics and its practical applications.

In answer to the final question, most of the residents felt that they handle the futility situation "fairly well". Ethics is learned at the bedside and they used "common sense" when they had to make decisions. The bedside model stems from Sir William

Osler, a great Canadian physician and educator, who stated,

> In what may be called the natural method of teaching, the student begins with the patient, continues with the patient and ends his studies with the patient using books and lectures as tools, as a means to an end... Teach him how to observe, give him plenty of facts to observe and the lessons will come out of the facts themselves. For the junior students in medicine and in surgery, it is a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself.[24]

A few examples were offered primarily involving families that contested resuscitation when a DNR order was written for an incompetent patient. What I did learn from this question was that "common sense" has different meanings. One group, the largest, echoed Schneiderman and Jecker's viewpoint (although they never heard of them). "Rabbi, families have no right to interfere. This is strictly a medical decision." Or, "What does the family know about medicine? How can families decide what's right?" One young lady resident was adamant, "It's the patient's decision. We know what's best for the patient. The family is irrational at a time like this."

Another group decided from "common sense" that the family should have the last word as if they were quoting from Lindemann-Nelson (although no one had heard of him). "Rabbi, how can we go against the family's wishes? It's cruel." Or, "We have to believe the family that it was the patient's wishes. Besides, we have no right to play God." (echoes of Veatch) One resident said, "Rabbi, I was paralyzed when the Code was called. I didn't know what to do. Do I resuscitate or not? It was in my hands. I felt it wasn't right. The guy was going to die anyway. In fact, he was already dead when we arrived. While the family was outside the room, I ordered a *slow* Code. We didn't tell the family, but they knew we tried."[25]

A third group said they placed their efforts towards convincing the family that to resuscitate was of no use (shades of Zawacki and Youngner). Some had succeeded, others failed. When I asked one resident, "How did you succeed in convincing the family?" She answered, "Rabbi, it took me a week, but I did it. I think they changed their mind when I explained - *Your father's last moments will be horrible. Resuscitation involves breaking ribs, stuffing tubes down his throat, giving needles and for no purpose. Even if we succeed, which is improbable, it is just for a few days or hours.* They seemed calmer and more accepting at this time, but it takes a lot of patience." As for the sub-group who failed to convince the family, they went along with staff doctors. "you go with the flow and don't push too hard, even if it is a very difficult situation and you are not sure it's the right thing to do."

Many of the conclusions derived from the interviews have also been previously observed in the symposiums, as mentioned above. Dr. Ho Ping Kong claims that,

> Although we send residents to the front lines, we often send them unarmed. They are often ill-prepared in medical school for clinical-ethical decision-making. They lack experience. They are forced to make difficult ethical decisions in emergency situations. This will no longer do. We must better equip our residents to deal with these clinical-ethical problems. We must not only teach our residents technical aspects of medicine; we must also develop systematic, rational and practical programs that teach residents how to identify, analyze and resolve clinical-ethical dilemmas.[26]

Dr. Peter A. Singer takes it a step further and claims that the teaching of ethics in itself is an ethical question, unless we can show that it improves clinical-ethical decision-making and the quality of patient care.[27] I would further claim that sending a resident to decide on ethical issues, especially on those pertaining to life and death,

when the resident is unprepared and has little knowledge in bioethics, is a major ethical issue. Does he have the right to impose his wishes upon a family in such an instance? On the other hand, how is a resident to learn if not through experience. Laura Weiss-Lane quotes M.J. Newton, who reflects on the ethical ambiguities of surgical training,

> If the surgical instructor could exercise complete control over the trainee at each step of the procedure or fully correct any problems that arose then the patient would, in essence, be under the care of the fully trained physician. Such is not the case. Several of the most delicate and critical manoeuvres involved in removing the cataractous lens are under the complete control of one operator and, once begun, can be neither interrupted nor transferred to more skilled hands... The trainee... must at some time... begin performing these *all or none* manoeuvres.[28]

Once again, we come back to Kinsella who wonders if staff physicians-in-charge of residents training are capable of quick decisions without the prior knowledge in bioethics.

Another problem touched upon in my interviews is that residents simply do not have the time for formal training because of the overwhelming demands of patient care. Because the workload is heavy, efficiency and curing are more important than caring. It is for this reason that they turn to the bedside model where case conferences are done in *ad hoc* fashion with everybody involved, using "common sense" to solve the ethical issue. It is also at this point that role-modelling is used as the effective method and the resident "goes with the flow" even if the role model physician is really inattentive and unable to cope with the ethical problem. Loewy emphasizes this in his critique defining the good role model. He seeks standards of judgement and writes as follows,

> Role models are important; but how do we know if someone is or is not a good role model? To make such a judgment, we must know the meaning of "good physician" not only as it pertains to the technical, but

> especially as it pertains to the humanistic functions integrated with the technical. Is the physician a "good" or "bad" role model if he/she efficiently and coldly calculates electrolyte deficits while failing to recognize the patient is more than an interesting set of circumstances?... Further, "good" role models in the sense that most of us would think of them - compassionate, sensitive, carefully trained scientifically, up-to-date individuals - are not easy to come by in most teaching programs. On what basis do we choose? Inevitably, our choice as to who admits patients and who is ultimately involved in resident teaching (like it or not) will be related not so much to the ethical dimension as to the technical and, in this day and age, to the economic: those who fill our beds are welcome, those who do not are not.[29]

As one resident said, "He is a terrific diagnostician and that's what counts."

Finally, I turn to examine two inappropriate aims of medical ethics education which I feel important to mention.[30] First, ethics training must not render any ethical position or decision as dogma. This is a danger which I personally note among a few physicians. There is a small textbook authored by Jonsen, Siegler, and Winslade titled Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine.[31] It is sad for me to see hospital physicians take out this handbook to decide as if it were the final word in medical ethics. Perhaps they need somebody to decide for them and whom they can quote as a source for their decisions. As I have said on many occasions, ethics is a process that must be worked out between parties with the knowledge, understanding, clarity and compassion. We must be able to listen, exchange ideas, absorb different viewpoints and work with patience.

For this is what patients and families seek; the concern and care which physicians and staff offer through the deliberations. It is not that they have arrived at the "right" answer, but how they arrived at the answer. It is not through trumping the family with a winning argument - for it is not a win or lose situation. In the end, the family knows

that we cared and struggled with them. That is the bottom line.

A second concern of Weiss-Lane is a belief that teaching medical ethics does not suddenly make a student or resident virtuous or moral. The knowledge of ethics by itself doesn't make a person more ethical. Students are not taught medicine to make them more healthy than others. They are taught technical medicine and medical ethics to provide them with the conceptual tools needed to solve problems. Weiss-Lane emphasizes,

> Though I believe that moral growth occurs through the process of ethical reflection upon personal experience, medical ethics educators should not aim to make their students "moral" through occasional lectures or even more intensive curricular interventions. Instead, it should allow medical students and physicians to refine their moral self-understanding and to put this knowledge to use.[32]

In conclusion, I offer a few personal observations. First, as mentioned above, students and residents are extremely busy learning and practicing "hard" and "practical" medicine. Learning ethics is a minor concern. Their workloads are heavy. They see the patient in a fragmented way, visiting for just a few moments unless there is a medical procedure to be performed. In their pockets they often keep cards in order to keep track of the practical needs of their patients such as medications, tests, etc. They read the cards before they enter the room. The staff doctor, too, briefly sees the patient on teaching rounds or in emergency situations. The upshot is that the older doctor-patient relationship has changed to stranger-patient relationship. We may now wonder at the role model they create in an era which needs an ethic of personal caring rather than an ethic of personal distance.

Second, there are frequent rotations of residents throughout the various services.

This, too, limits their ability to get to know the patients or even the senior physicians who are their mentors. The departments are also fragmented politically and socially. Often the staff doctor does not know the resident very well. They keep their distance. Levine writes:

> For example, Departments of Medicine or Surgery used to function rather like communities. All members of the community, including senior physicians, junior physicians and postgraduate students became familiar with each other as people. They went to most of the same conferences and they went to most of the same social functions. For various reasons, this has ceased to exist in the typical university hospital... Fragmentation of the community makes it more difficult to teach ethics in ways that go far beyond the difficulty in assembling the students for their courses and conferences. With such fragmentation, there is a tendency for bureaucratic values to replace those of responsibility and commitment for an ethics of strangers to prevail over an ethics of caring.[33]

In our hospital, a prevailing humourous observation is "the staff physicians fear the residents (who cover for them) who in turn fear the nurses (who do a great deal of teaching) who in turn fear the orderlies (who do their dirty work)".[34]

There is a third major reason for this lack of communication between doctors and patients. There exist province and hospital-wide pressures for physician and residents to get rid of patients, not to keep them on the floor, send them home as soon as possible. In turn, this pressures nursing, social workers, pastoral services, and especially the discharge team who all have to answer questions from patients and families who are not ready or capable to accept the patient at home. We call this the "revolving door syndrome" where patients are sent home and returned in a short time, often in worse condition than when they first arrived.

I recall a story related to me by our Chief of Nephrology who was conducting

medical rounds for his junior staff in which he described an interesting case, trying to elicit comments from the residents. The nephrologist was excited about this case because it was a rarity - an important learning experience for his students. He related to me that the discussion which ensued was going very well when one of the residents piped up, "When can the patient be told to go home?". Our nephrologist continued, "Rabbi, I didn't know whether to scream or cry." What is happening to our teaching process? What has happened to our whole health care system? The question this resident asked was not his doing. He was just emphasizing a major hospital concern to release the patient as soon as possible. It is all very sad!" I wondered out loud, "Doc, how do you teach ethics in such an atmosphere?" He answered, "Ethics? It's tough - very tough. I don't know how you do it."

But ethics is not dead. It only appears to be distant, remote. It is alive and well. The students and residents are generally sensitive and caring. They chose to be physicians because they genuinely wish to contribute towards a healthier community. Part of the challenge is teaching ethics. The residents and students are confronted daily with ethical issues and they want to learn and know how to handle them. It is difficult enough to bear the heavy burden of the patient's physical needs, but it is more difficult when the resident has to bear the responsibility of ceasing treatment when it is not therapeutic, or to have to share thoughts when a patient dies without someone to listen, or to be given the responsibility to give the patient hope when there is little to offer and, especially, when they have no experience of how to communicate to patients and families. It is difficult enough when residents are physically and mentally exhausted, to

be called after midnight to the neonatal ICU, but it is more difficult when the resident agonizes over which is more loving and humane: to artificially prolong an infant's poor quality of life or let nature take its course. And how do we treat autonomy when information given is selected by a senior physician whose ego is monumental, claiming that he knows so much more than the patient, and the resident must follow instructions from his mentor whose personal values and biases and experience influence how much the patient should be told.

My research of the resident physician and his/her training in medical ethics shows many similarities in the difficulties and problems we have seen with the medical student. Basically, the bottom line is the relative unimportance of medical ethics in the education process. Ethics has been relegated to the reliance upon the "common sense" approach towards solving ethical issues in medical practice. The educational methods of teaching ethics do not seem to have a meaningful impact upon the students. The students and residents, under the stress of fulfilling the medical needs of their patients, do not seem to have the time to grasp the relevance of medical ethics. The result is that the students and residents are really unprepared to handle any dialogue in ethically-charged situations such as medical futility. Even the role model approach is questionable. This is evident as we hear the residents "going with the flow" - not having the comfort to freely ask if there could be other ways to handle the situation. In addition, the staff physician and residents are not prepared, nor have they been trained to deal with difficult ethical issues. The upshot is that the problem is ignored, rationalized, "swept under the rug", or simply abandoned with the excuse that physicians are there to cure, while caring is a secondary

matter. It may be that this *laissez faire* attitude is due to the relative newness of medical ethics as a professional course and discipline. It is a program which may take time to develop, especially under the present medical model approach and financial shortages that universities and hospitals are enduring. Everyone agrees about its importance, but it is difficult to instill into the system.

There may be a few lessons to learn and some suggestions to offer under the circumstances. I realize that implementation of any program under the present pressures may be difficult; nonetheless, we have to start somewhere.

1. The codes of the Canadian Medical Association of medical practice and ethics should be stressed. This should be a professional requirement before graduation and exams should require passing grades. It would serve as a wake-up call towards professional integrity and the importance of ethics.
2. The teaching of medical ethics should be organized as monthly hospital rounds. It should be standardized by the students and residents with case presentations from the various wards. These rounds should be supervised by staff physicians and university and hospital ethicists. There should be representation from the Ethics Committee. From my experience, it may take time to develop, but we should persevere. It is most important to create a sensitivity to the moral and ethics issues surrounding many of our cases.
3. When rounding on the floor, family members should be invited to listen with the permission of the patient. Traditionally, family members are excluded from medical rounds. These rounds have been sacro-sanct from the medical

community - almost as confidential as the medical chart. In my opinion, however, family members should be invited to listen, ask questions, and be explained in lay terms about the medical situation. This may alleviate any misunderstanding, dissatisfaction and conflict which could arise. As well, it might be a positive influence on the medical team in terms of humanizing care, individualizing each case and explaining the implications to family members and fostering better communication.

4. There is a standard myth about the difficulties in establishing a rapport of trust with patients and families. Virtually all of the ethicists quoted in Chapter 2 are concerned with establishing patient trust. Trust is endemic to all physician/patient relationships. The general belief is that it may take time to establish trusting relationships. While this may be true for some patients and families, it can be relatively simple for the majority. For example, the doctor enters the room. The patient is partly uncovered. The doctor, after introducing himself, takes the blanket and covers the patient. "Mrs. A, you are going to catch cold if you don't cover yourself." Or, "Mr. B, are the blankets too warm for you?" Or, "Mrs. C, you look like you are thirsty. Can I give you some water?" Or, "Mr. D, your pillow is not positioned right. Let me help you." With this approach, a rapport has been established. I'd come into the room after the doctors left and I hear, "Rabbi, what a doctor! He really cares."

In my opinion, patients and families are vulnerable, seeking attention. They

come into Emergency. They are afraid. The bed is strange, uncomfortable and they wait and wait for some attention. The family bringing in the patient is anxious. The patient complains. Doctors and nurses pass by their cubicles and beds, running to attend other patients. Finally, a doctor comes by and sits down. "Tell me your problem." "Are you in pain?" "I am here to help you." Just sitting down makes a difference. Just holding a hand, wiping a brow makes a difference. Dr. Gerry Dankoff, a senior physician in Emergency, is quoted in *Pulse* (the Jewish General Hospital staff newsletter), "Patients who are brought into the Emergency are often *desperate people in a desperate place*. They may have difficulty trusting anonymous doctors whom they have never met before, particularly if they have been misdiagnosed in the past and they have unrealistic expectations of what can be done for them." Other potential barriers to effective communication are the influence of gender, culture and language, poverty, poor education and a violent behaviour. Physicians, noted Dr. Dankoff, are also in a desperate situation, pressured to act quickly to free up beds, etc.

Establishing rapport under these circumstances is not as difficult as it seems. Observe the patient's non-verbal body language and choose to interact at that level and be sensitive to the patient's way of answering questions in the words he chooses, suggested Dr. Dankoff. "What is the most important thing for a physician to remember? Remember that you are human and that will help you empathize with the person in front of you", he concluded. This approach has a

few rewards. Aside from establishing a rapport with the patient, the doctor becomes a friend. It also minimizes the distance the training places between resident and patient.

5. Finally, the major key to student and resident training remains in the hands of the staff physician. Dr. Horlich simply says that "the single most profound influence on residents is the attitude of the attending physician towards the patient."[35] This, indeed, is the bottom line. We learn from our mentors. We absorb their attitudes and approaches towards the patient and families. The future of our whole medical system is dependent upon the ethics of justice and caring towards patients who are ill and most vulnerable because they are dependent upon us.

The Physician, Government and Hospital Administration

A typical day in our Chaplaincy office invariably includes some emergency phone calls. "Rabbi, I'm phoning for my mother who has multiple problems. Our regular general practitioner is really too busy to serve us. We have to wait for hours to see him and then just for a few moments. I want to change doctors. Can you recommend a name for me?" After I suggest a list of physicians to the caller, he chooses one and then I hear the crunching question, "Rabbi, do you think you can make an appointment for us? The doctor really doesn't know us. He probably won't see us for weeks or months. See what you can do." Another call comes through upon a similar request. "Rabbi, they have given my mother an appointment for a CT scan in three months. Do you think you

can hurry it up? She really isn't well." A third call comes through at ten o'clock in the evening. "Rabbi, my father is in pain. It's his stomach. I hate to bring him into the Emergency. He will have to wait for hours. He is an elderly gentleman. Do you know of any doctors associated with the hospital who would make a house call?" I tell him, "Unfortunately, doctors today hesitate to make any house calls. Bring him down to the Emergency." Then I hear, "Rabbi, do you think you can meet us there so that they can rush us through?"

These are just a few of the many scenarios patients and families are experiencing within our present medical system. Indeed, we are going through very difficult times. One could argue with the caller and say, "It's not really fair or ethical on my part to squeeze your father in before others who are patiently waiting their turns. Further, if I accommodate you, everyone will be squeezed for time - the doctors and the patients - it won't be fair for anybody." The fact is, however, father is in pain. The family is obviously frantic. Where can they turn to? Whom shall they call? The father is probably in his eighties. They become paralyzed with fear. Someone says, "phone the Rabbi".

Every time I get these calls, I think of a story about the late Judge Harry Batshaw, whom I met in Emergency about fifteen years ago. The judge had broken his leg, was in obvious pain, sitting on a wheelchair with his leg up in a straight horizontal position. He had a number card in his hand which showed Number 42. I was down in Emergency and they were calling Number 17. The judge had at least a two or three hour wait in order to be served. I recognized the judge, introduced myself and smugly said,

"Judge, I'm going to get you in right now. You just wait here for a couple of minutes." I ran into the hub of our Emergency area and spoke to the doctor in charge and we both came out into the waiting room. The doctor whispered to the judge, "Judge, you have served the Jewish community with impeccable distinction and honour. Now we are going to pay you back." He looked at us and said, "I'm Number 42 and I'm going to wait my turn." The doctor said, "But Judge, you are in pain. It's really a pleasure to serve you." In a raised firm voice, the judge retorted, "Young man, I'm Number 42, not Number 41, so you go back to your work so I can get in quicker."

The phone calls come through. I think of the judge, but I say nothing. It's a father. What would I do with my father? Probably the same - try to get him in as quickly as possible. Besides, it's not a time to argue.

What has happened to the medicare system, a system which made us so proud to be Canadians? When someone would ask me, "What is a Canadian? Why am I different than an American?" I think firstly of medicare and that all Canadians have access to one of the best health care systems in the world. But this is changing. The system has serious problems and the cracks are visible. Doctors blame the government, claiming that patients are abusing the system. Patients and families fault the government, arguing that physicians ruined medicine by seeing as many patients as possible in order to claim greater fees from medicare. The government argues that hospitals are overstaffed. Hospital administrators point to higher costs in technology, drugs and nursing. The upshot is that government has stepped in. The aim is now to balance the budget. Our health care system has become a major scapegoat for our financial ills.

The purpose of the research is not to seek fault or even the source of our problems. My interest lies not in who is right or wrong, what is ethical and what is not. I am dealing with perceptions and feelings of how physicians, patients and families experience the system which makes us all struggle. However, before we can understand how physicians feel and comprehend the situation, let us take inventory of how they view what is happening to the system in general. The point I am trying to make is that hospitals and physicians are in the throes of very difficult times. Coping with ethical issues is generally not perceived as important and this lack of stress on ethics may influence our view on how we look at futility. It is not unreasonable to believe that in an era of cutbacks and shortages of beds, the value of prolonging life at higher costs has become sadly weakened. Thus, the physician's view of futility in end-of-life issues, especially in the older patient, may not be as major an issue as it has been in the past.

Government Strategy[36]

A major provincial strategy in Quebec and other provinces in downsizing government deficits has been the move towards global hospital financing. The province of Quebec's formula is based on the hospital's past expenditures and the population it serves. The individual hospital or regional hospital authority must then calculate how to work within the framework of the budget. While this places a cap on how much each hospital receives, the Quebec government has also shut its eyes to the consequences of many hospital closings. An additional burden, financial, physical and psychological, has

been placed upon hospitals which have taken up the thousands of patients displaced from the hospitals now closed. Further, our hospital was forced to take some eighty full-time employees from other hospitals after being warned that we must reduce our budget. One hospital administrator complained, "As much as the government tries to reduce our budgets, they have burdened us with highly paid employees and thousands of patients for which we are receiving not one cent in return. In fact, we are getting additional cuts and anticipate further cuts in the near future."

A second strategy was to encourage the buy-out option in which hospitals were urged to buy-out the contracts of employees before retirement years. The premise was that hospitals were overstaffed and many employees were not really pulling their weight. They could be replaced by others in the department or by cheaper labour if necessary. This offer of early retirement was made to all employees of pre-retirement age. The result, in our hospital, was that some very key and productive employees, including excellent nursing, administration, and general employees, took the offer, leaving a void in patient care and the general competence of the hospital's workings. In fact, some of these same employees were re-hired as consultants after the buy-out because of the void left in many departments. These cutbacks, buy-outs, and overload of newer patients have brought a pall of sadness throughout the hospital. The strain has been overwhelming for some who find the present burden too much to handle, including the loss of friends with whom they worked for many years.

Further to the cutbacks, buy-outs were tendered to physicians. It was assumed that Quebec had too many physicians and that there had to be an increase in patient-

doctor ratios. The method to increase this ratio was to lower payments for services and buy out the older physicians with early retirement packages. This was part of the strategic government move called *Virage Ambulatoire* which would open more out-patient services, outside clinics and CLSCs (Centres locaux de services communautaires). This would relieve pressure on the hospitals and result in less need for the abundance of doctors in the province. The result, according to the Montreal Gazette headline and article of May 12th, 1998, was that

> Medical clinics in and around Montreal are running on empty with their doctors either overworked or refusing to practice because the government won't let them make more money... Call it a problem of supply and demand - not enough doctors, too many patients - aggravated by Quebec's drive to cut the deficit. It has happened in Quebec because Quebec is training too few new doctors and is buying out the older ones with early retirement packages. Those remaining see so many patients that they reach their government-imposed pay ceilings too quickly so they stop working. This puts even more pressure on other doctors - as well as the patients. People have to wait longer to be seen. When they finally get in, they are rushed through their examination...
>
> Paycaps aren't the only problem. Quebec, and especially Montreal, have been losing GPs to early retirement; many over fifty have taken their buy-outs and set up in other provinces. Young medical residents coming out of medical school aren't taking their place; to promote health care in rural regions, the government pays only 70% of full-scale for practicing in the city. *We've lost on both ends of the spectrum, and the few doctors that are left in the middle are trying to carry on seeing patients, more serious cases too, because of the virage ambulatoire.* Mootsawmy (Director of the Stat Care Clinic of Montreal) said, *CLSCs are not open on weekends, and sometimes even during the week they can't cope and are sending people to us....*
>
> *In Pierrefonds, patients will pay the price for the clinic's problems*, predicted radiologist Henry Soliman, who quit practicing at the Lakeshore General a year ago and now spends his time with three West Island clinics. *With Pierrefonds closing for two weeks, the waiting list for services like mammography and other clinics will lengthen to three or four months*, he said. That's a long time to wait for a test, especially if you think you might have breast cancer.[37]

The gravest part of the "buy-out" option reflects a government policy which emphasizes that these are not temporary measures but part of an overall government strategy for health care. Buy-outs represent an outlay of millions of dollars which is supposed to prove money-saving in the long run. The goal strictly stems from a financial view - looking into a distant future without really knowing what that future holds in store. Second, in their efforts to universalize the buy-out options, offering it to all employees, we have lost some of the best and most productive people. This has, in many cases, downgraded the efficiency of many hospital departments. There is now less staff and the burdens have been placed upon those who remain who are not really competent to handle the overload. Third, as mentioned above, it has brought about a sorrowful and depressing attitude for many of the remaining employees. We realize that buy-outs are a long-term measure, but the situation will probably get worse before it gets better. The government has charted its course. Patients suffer and staff is overworked. It's difficult to watch many dedicated doctors and nurses working under this cloud of an uncertain future in a health system which they are trying to make better, often through heroic efforts. Finally, even if some money will be released by governments into the system, we are losing the battle with each passing day. As technology and medications improve, we live longer and thus patients are older and more sick. The concept of caring is not only for the ninety day stay in palliative care. It is also for the many other patients with a variety of illnesses who will need lengthy hospitalizations or home care. Finally, as mentioned above, the government has charted its course. Health care will no longer be permitted to drain the economy. According to hospital administration, all

additional funding will probably be like a band-aid on a body which sorely needs major repair.

Hospital Strategies

Stemming from inadequate global budgets, hospitals have responded to increased financial pressures in different ways. Beneath these strategies lies a fundamental belief in the medical model of health care. In this approach, "medical care is understood as a scientifically determined diagnosis of a problem in a particular part that is largely unconnected to the rest. Only if it is assumed that the part can be treated with either cuts or chemicals, without attention to the psychological state of the person or consideration of the social context before and after treatment, can quality be assessed in terms of lengths of hospital stays and numbers of procedures."[38] This model permeates every decision hospitals are devising in order to satisfy its goals and purposes.

Within this context, hospital strategies include closing beds, cutting staff, shortening patient stays, performing more day surgery, and enlarging out-patient facilities. There has also been a movement to standardize services and move long-term care patients into the community where they mainly wish to go and not be subject to the indignation and lack of cleanliness of many of our hospitals. There is no place like home.

There are, however, serious problems within each category. Closing beds places enormous pressures on Emergency departments. The doctor must decide or even "play

God" about who gets the available bed. Is it the older frail patient who has nowhere to go and needs placement or the younger patient who has a chance for a cure? Is it the complicated case or the sad case of a terminally ill individual where home care isn't adequate? And in any case, if beds are at a premium and the more complicated or serious cases are admitted, then the hospital has defeated its primary purpose - to save money - because each patient may need more expensive care and the turnover will not be quick enough to allow the patients up from Emergency.

And even if, within this medical model, we are able to justify sending the patient home because we have solved the immediate medical problem, we wonder if the patient has not been rushed too quickly out of hospital and if he will return very shortly. I visit a patient's room and often hear in Yiddish, "Rabbi, why are they pushing me out to go home? I'm so weak. I'm not a youngster. I have no *ko'ach* (strength). Who is going to take care of me? And if I come back, will I have to go through Emergency again and wait for hours?" The patient has a point and has touched upon another issue. What happens to the patient who does not speak English or French fluently and does not understand too clearly what the nurses and the staff in general are trying to tell him, especially upon discharge? Older patients are frightened and they revert to languages of their youth where they feel most comfortable.

Another major change in hospital policy has been the establishment of mixed gender rooms. This has been implemented because of bed shortages. Patients are sent from Emergency to rooms without consideration of gender. The philosophy is, "A bed is available. Let's make use of it." The result is that many patients, especially the

elderly, resent being placed in rooms with people of the opposite sex. Some ladies and gentlemen of all faiths who have lived a religious or modest life find it difficult to accept. "Rabbi, this is wrong. Sometimes my neighbour unwittingly uncovers himself/herself." Or, "I always have to keep my curtain drawn. It's not fair." Or, "Her curtains are blocking the window." Sometimes a family member calls, "Rabbi, can you get them to change my mother's room. She doesn't like to complain, but she's very uncomfortable."

And as we accept the reality of fewer hospital beds, it does not mean that there will be more time for patient care, for we also have to cope with shortages in nursing. What happens if patients are alone, have no relatives, or have relatives far from home, and few, if any, visitors? Further, because of the bed shortages, many patients are sent "off-service" on wards where they do not belong. They are placed there only because a bed was available. In many such cases, there is a discontinuity and fragmentation of service. Doctors have to chase after these off-service patients. Sometimes they do not see the patient and the patient falls through the cracks. Oft times, we also hear doctors and nurses talking about the CA (cancer patient) in Room 728 or the CVA (stroke patient) in Room 398 or "How is my CHF (chronic heart failure patient) in Room 835 or my PVS (permanent vegetative state) in Room 415?" We point out that the patients are not only CAs, CVAs, CHFs, or PVSs; they are whole human beings not only with names but with feelings. They deserve our full attention and recognition, especially as they are hospitalized. This, too, reflects that the medical model is inadequate as it does not serve the "whole" patient. We are only interested in the present medical situation and our aim is to get the patient out as soon as possible.

Cutting staff equally increases health risks. In an interview with nurses, they complain that staff has been reduced in certain areas of the hospital up to 40% from the 1993 level. One head nurse told me,

> "Rabbi, many nurses are simple working mothers. The pressures are huge with all the uncertainty over budget cuts. There is an ominous cloud overhead. There isn't the job satisfaction we all sought when we went into the profession. When one of our kids is sick, we cover for one another. We have no time to communicate to the patients, to ask how they will manage at home or to comfort them. We have no time to work with families and we feel guilty. The complaints pour in. Families are upset and demand more. At one time we could help feed patients, we haven't got the time anymore. If the tray is untouched, we know the patient hasn't eaten. It's awful. At one time, we had twenty minutes allotted for a bath. Now it's half that time. And how can we allot time for bathing when each patient's needs are different?"

Shorter hospital stays can be a blessing for those who are able to leave and have outside and home resources. Hospitals are not the best place to stay, especially in our times. Some wards reek with infectious diseases. The food is certainly not the greatest, unless you are dieting. With shortages in nursing, cleaning staff, and having to wait to get the attention of a staff doctor for a few moments or medical residents who disappear on weekends, all these can make a stay most unpleasant. If you are able, it's best to go home.

But shorter stays can also be frightening, dangerous and costly in the long run. Much involved in short-term stays is the Discharge Planning Team. This group consists primarily of specialized nurses, social service and out-patient services, who are in touch with the wards, to make certain that the patients who are discharged have the appropriate medical and home support system when they leave hospital. In an interview with the head of this team, I was told of a study performed in our hospital and others in the

McGill hospital teaching group.[39] This study followed patients who were given instructions and the follow-up understanding and implementation of these instructions. It was found that the greater percentage of these patients and families did not remember receiving all the instructions. They did recall "something", but they did not truly understand what they were told. Secondly, patients are sometimes discharged with dressings that have to be changed or even with catheters. Families are terrified. Oft times it's an 85 year-old wife who is the caretaker. To quote the head of Discharge Planning, "Families and caretakers have to be trained, but who is to do the training? Their return to our hospital Emergency is almost predictable and often they have to remain longer because of the complications on this second stay." Third, the CLSCs who are supposed to assist in such cases are overloaded. They, too, suffer from the shortage of physicians and nurses. From the beginning, they weren't synchronized or prepared for the amount of hospital short-term discharges. Fourth, there are serious shortages of convalescent beds. The convalescent hospitals have now become rehab institutions and if the patient is not in rehab, there is no bed available. Fifth, the concept of discharge planning begins almost upon the patient's arrival. This places a great stress upon the medical residents and staff who prefer not to think about discharge at this time. It also has a frightening effect upon the family when you speak to them about discharge upon the patient's arrival. It is as if the hospital is telling everyone to "hurry it up" and let the patient out when this family is concerned about patient care and cure. And often the patient gets "fed up" and says, "Get me out of here. They are really not interested in me." This is why many families insist on sitters and primary nursing care so that the

patient will not feel abandoned. There are further stresses, social, psychological and monetary. Let us take a fairly typical case of a 65 year-old gentleman with a history of minor strokes rushed into hospital to be treated for congestive heart failure and pneumonia. In the course of his treatment, he is given an antibiotic which suddenly gives him serious adverse effects. He develops diarrhea - which is controlled - but finds himself very weak and suddenly incontinent. Because the diarrhea has been controlled, he is sent home to his wife, who is working to support the family, and his daughter who is still in university.

According to the medical model, the gentleman has been completely fixed up. All he needs is custodial help. His wife is nervous. She doesn't have the skill or time to help. He needs assistance and the family can't afford it. Medical bills mount because his special medication is bought outside the hospital. The patient senses his anxiety and calls 911 to get re-admitted. The ambulance comes and takes him to the Emergency. They keep him overnight for observation. In the morning, they want to send him home. "There is nothing special we have to dó for you to warrant keeping you here." The patient is adamant. A hassle begins. "I'm not going home. I'm too sick to go home." Discharge Planning calls Social Services and the wheels begin to turn. The whole truth about the family's situation is told. The result is that the patient is not to leave the hospital until he has the proper home care.

What does this story tell us? What if the patient was the wife - the breadwinner of the family? What if the patient was not so adamant in regard to being sent home without sufficient help the second time (as many families' experience)? Families, most

times, feel that they have no choice. And what happens when the wife hurts her back as she takes her husband to the bathroom or helps to bathe him? Today, many caregivers do not have the proper skills, although they may be loving and dedicated. And what if the wife develops an infection, cold, flu, fever, from handling the patient? The bottom line is - the government can save money with short-term stays. For some families, it is a blessing, but for so many others it is dangerous and can develop into a recurring nightmare which in the long run costs the hospital system much more than anticipated.

Similar situations and problems occur in day surgery and out-patient clinics. Although for many, clinics and day surgery are a blessing, they can be hazardous and terrifying. Once again, both concepts reinforce the medical model without concern for treating the whole patient. They are only interested in the immediate physical problem and have no interest in the psychosocial consequences which will automatically arise from the surgery and visit to the clinic. Both environments, in this sense, are quite sterile. In day surgery, the patients are lined up as if in an assembly line. The nurse has little time to communicate or to get to know the patient. Speed is a priority. Quality is defined by how long it takes and how many patients are handled in a day. Everyone who enters a hospital is usually frightened, afraid of the outcome. The forms that one signs leave little time for any contact with the doctor or nurse. Pat and Hugh Armstrong describe a case presented to them,

> "My doctor booked me for day surgery for a sinus operation. It was supposed to be real easy. "No big procedure - no big problem", the doctor said. In fact, I was scheduled to return to work the following day.
>
> Anyway, I went to the hospital at 2:00 PM and was given a general. I woke up at 5:00 PM. It was like a minute. I came to; they were trying to push me out. I can tell you, I felt awful; dizzy, feverish,

> not really alert, and sick from the anesthetic. There was a kind of commotion on the floor. They were trying to get everyone dressed and out because it was the end of the day and they were trying to clear the surgery. I told the nurse that I wasn't feeling well, but I was handed my dentures and told to go home and rest. They hadn't taken my blood pressure, temperature or anything - so how did they know that I was okay to go? My partner was concerned and asked shouldn't I be checked by a doctor before I left? But he was told there was no doctor because it was day surgery and we were supposed to be out, never mind our conditions.
>
> On my way home, only an hour later, I started really feeling ill. I figure I was just beginning to go into shock because my partner said I wasn't making sense. The bandage around my nose was drenched with blood. I was dizzy and felt kind of clumsy. My partner drove me as fast as he could to another hospital. I was in shock by the time I got there from the blood loss, so they admitted me immediately. He had to pull all the packing out and catherize the right side of the nose.
>
> Being treated like a piece of meat - so brutally when you are so vulnerable - has left my nerves in a terrible state. It has actually scared the hell out of me. You know, it's like you really don't matter. Day surgery has its rules and if you don't heal like you are supposed to, well that's too bad. You are out the door anyway. Never mind if you live or die or get really sick. Never mind. It's the rules.
>
> This has triggered so many bad memories for me, so much stuff from my past. I haven't been able to go back to work. I feel absolutely that they can't treat anyone like this. It's wrong. It's terrible medicine, it's leaving people scared."[40]

The patients in day surgery are often elderly people. After leaving the hospital, many still require a great deal of care even within the limits of the medical model. Now, as the patient goes home, they usually have unpaid and untrained help. And if they have to come back to the hospital clinic, they are counted as new patients, not as older ones who need further hospital assistance. This adds to numbers and demonstrates the hospital's success.

The movement towards outpatient clinics, too, has its many problems. The original concept was taken from the distinction between acute and custodial care. Clearly, not every patient needs hospitalization. Custodial home care could even prove

more beneficial to the patient's well being. However, the numbers served in out-patient clinics tell us very little about the quality of care. The pressure to release patients as soon as possible emphasizes the quick and fast medical approach. Oftimes, patients are released after a simple test or even before having conclusive results of the test. They are told, "we will advise you of the results when we get them." This places the patient, families and caregivers in danger through the spread of disease and in the process they may not only risk their own health but may also add to the cost of the system. Further, the nature of this fast transitory approach means that the patient will often meet different doctors at each of the clinic visits. This translates into brief encounters with health care givers who know little about the patient as a whole. Once again, the medical model is reinforced. The patient is seen in the framework of "work-efficiency" which does not relate to the quality of care but to how many patients were seen and released. It's as if the clinics were operating on a production schedule. An older patient complained to me, "Rabbi, the doctor saw me for a half minute, prescribed an anti-inflammatory medication for my pain without realizing that I have a stomach problem which forbids me to take such medication. I almost died." This, too, is symptomatic of the quick fix of many illnesses where, on the basis of a simple test, medications are given without question to so many of our elderly. The Armstrongs write, "Patients are variable; risks are different and the whole thinking, feeling, person, not a mechanical part, is at stake."[41]

An outgrowth of these government and hospital measures has been an increasing interest in developing a formula for typical length of hospital stays by the nature of the specific illness. For instance, by-pass heart surgery should take no longer than eight

days. Breast cancer surgery - no longer than a week. Hysterectomy surgery - four days, child birth - forty-eight hours. This is similar to the American system where insurance companies promote managed care in their HMOs (Health Maintenance Organizations), which will only pay for certain lengths of stay depending upon the surgical procedure and illness.

There is a rationale to this approach - other than financial considerations. In an article titled, "The Case for Using Industrial Quality Management Science in Health Care Organizations"[42], the authors declare that elimination of unnecessary variations in clinical practice may improve the quality of care. In other words, quality of care is defined in terms of the extent to which everyone is treated equally. There is too much variation among physicians which unnecessarily prolongs the hospital stay. The aim is to standardize medical treatments so that it will be fair for all concerned. Governments would then be in a better position to plan for the future. Doctors and nurses would then be able to reassess their overall practices and eliminate unnecessary procedures.

But it's not simple. The Armstrongs argue,

> The elimination of variation may well be the best strategy when chocolates are being made, but this is not the case when individuals are being treated. As we have seen, medicine is an art as well as a science. Single causes and single solutions cannot be scientifically determined for whole people. And people do not come in standard packages with standard responses. Pregnancy or breast cancer are not precisely the same from woman to woman. In fact, no two pregnancies or breast cancers, even in the same woman, are exactly the same. The variation results not only from their individual physiology and the changes in this physiology over time, but also from their individual, social, environmental, and psychological conditions. Culture also plays a role. And each patient is now more likely to differ as hospital admissions are increasingly being restricted to the most complicated cases.[43]

There are also problems with the data collected. Steven Lewis points this out,

> The very notion of "better" is defined by values, probabilities, preferences, risk assessments, technical capabilities, and opportunity costs.... More and more of medical practice is becoming discretionary as the possibilities and tools for prevention proliferate. In the absence of frameworks for assessing the value of these interventions in various circumstances, our storehouse of data is increasing at a far faster rate than our ability to incorporate it into coherent and transparently fair allocative decisions.[44]

The data are also about procedures used, the numbers of hours of surgery in each case, and the amount of necessary medication given, but they do not describe the person, his comfort, and his satisfaction, and in the long run, many hospitals treat re-admissions resulting from complications as new patients, as I pointed out earlier. And what happens if patients are admitted to another hospital because of overcrowding or because of an ambulance ban in the original place of hospitalization? Because of these arguments, it is very difficult to be certain that governments are saving money with shorter hospitalizations. The shorter stay may represent inadequate, rather than quality, care. The variability in surgical and medical treatment does not mean that physicians are applying inappropriate treatment. It means that patients are different even with the same illness. Their capacities to fight illnesses are different because their physical and psychological make-ups are different. For this reason, medicine has never been an exact science. The physician must be skillful, combining both attibutes of science and art in dealing with each patient as an individual. One of our hospital's leading physicians in Infectious Diseases summed it up, "If governments will move to standardize our practice, they are stupid. It will be the end of medicine as we know it."

The upshot of these moves on the part of government policy has been to make it

difficult for the hospital staff. The staff is now judged on productivity rather than competence and compassion. In the United States, physicians are well compensated. They earn double and sometimes triple the salaries of their Canadian counterparts. Towards the staff in general, it's almost as if our government is schizophrenic. On one hand, they boast of good quick service and of their accomplishments while balancing the budget, and on the other hand, they are forcing hospitals to close beds and physicians and specialists to close their offices because of curbing fees. From another view, we see that they demand and expect excellence in each area of the hospital in order to receive accreditation, while at the same time, they are forcing the administration to cut back all services. Hospital staff including nursing are expected to work doubly hard because of the buy-outs and the policy of not hiring to replace those who leave. Simply put, governments are asking for coverage while squeezing the system financially and making it impossible to do a proper job. This takes its toll on the morale of our hospital employees. The irony of it all is that all these cutbacks in our age of technological advancements reinforce the need for ethical solutions. We now have newer ethical dilemnas to deal with. What shall we do with doctors who threaten strikes? Do doctors have the right to strike? What should we do with patients who are not treated properly and sent home before full recovery? What shall we do with disgruntled nurses who are working overtime and do not get paid accordingly? What shall be done for patients who complain of overcrowding in Emergency rooms because there are no beds on the floor? How do we cope with patients who can't find a doctor to answer simple questions? And so the more traditional esoteric issues in ethics from the beginning of life to the end -

such as genetic testing and engineering to end of life issues as resuscitation and euthanasia -have become luxurious and almost unimportant in contrast with new basic ethical problems. In an article titled, "The End of Medical Ethics", A.R. Jonsen[45] writes, "The thesis of this essay is that, to the extent that the structural changes in the institutions of health care, taken cumulatively, deprive physicians of the authority appropriate to their work, a distinctive ethics of medicine becomes less and less necessary. The thick volume in which the ethical admonitions and practices of twenty-five centuries has been collected, will become a rare book in the library of medical history. It will have no relevance to modern practice." I believe that Jonsen has a legitimte argument, not for his concern about the erosion of the physician's authority, but because governments now have balancing budgets as their major priority. Thus, the whole concept of medical ethics has been jeopardized. We could find ourselves watering down any philosophical or ethical approach into a forced pragmatic sensible thing to do under the circumstances. At best, most of our ethics would be covering rationing health care and who gets the dialysis or a hospital bed. If we keep debating this principle for selecting or de-selecting patients, we endorse a belief that the focus of our moral concern is on whom to exclude. This provides the "solution" to the health care cost crisis with a stamp of "approved by the ethical standards of the General Hospital of Montreal". Scenarios could vary, but in the end it is these budgetary restraints which will control our thinking and decision-making. But it is more than an ethical issue; it involves the caregivers, their morale and spirits and in the end it will affect patient care. It is not a matter anymore of who gets the bed. The basic needs of patients are affected and this

is the bottom line.

Quebec's vision in 1995 of the *virage ambulatoire* was at first an inviting approach to reform the health care system. The idea of moving people back to the community as soon as possible was appealing to many who would rather recuperate at home than in hospital. The plan was immediately put into operation by the Regional Health Boards. Unfortunately, there are problems which have not been dealt with.

Shorter hospital stays and one-day surgeries require community resources. This has resulted in a shift of responsibilities to family and friends, mostly women, creating tremendous pressures. In many instances, people have fallen through the cracks and have been released into the community with very little support, while others simply feel insecure about the health care system in general. Further, the inadequacy of resources facilitates the emergence of private services and contributes to the destruction of our universal health care system.

The cuts have also had a fundamental impact on the nature of the system itself. As public resources have deteriorated, services in many areas have been privatized, such as laboratories, physiotherapy clinics and optometry services, and operations such as cateract surgery are available for those who can afford to pay and avoid the waiting lists. The transition is to a two-tiered health care system, one for the rich and one for the poor. This raises serious concerns about financial accessibility. What will happen to the person who simply cannot afford to pay for transportation or home care services? What about the person who is released from hospital and can't afford to pay for the medication he or she would have received in the hospital? Finally, the pressures placed upon

medical residents and physicians to release patients as soon as possible have placed the whole concept of medical ethics in a new light as either becoming a too time-consuming luxury process or one which has little relevance for our time.

Staff Physicians and the Hospital

Up to the present I have mainly emphasized the strategies of governments and hospital administration and their effects on the patient population. I also quoted, at length, from the *Montreal Gazette* a physician's view from outside the hospital. I now turn to GFTs (geographic full-time) in-hospital physicians and surgeons. How do they view the situation? What are their arguments and complaints and what do they see for the future?

First and foremost is their concern about the lack of newer medical equipment and machinery, which is so readily available south of the border. For instance, there are not enough CT scanners, ultrasound equipment, gamma cameras and other equipment for our Nuclear Medicine Department. There are only six MRIs for all of Montreal, as opposed to approximately one hundred and seventy-five each for Chicago, Miami and Philadelphia. Staffing for the equipment on hand is at a bare minimum. Presently, the average wait for ultrasound is from four to six months, CT scans - one to five months, depending on the urgency of the case. Even women anxiously waiting for results on breast biopsies wait as long as four weeks.[46] Physicians tell me, "without the MRIs, mistakes are made in diagnosis. Patients and families are aware of this. They are

extremely well informed." "The government is content with mediocrity. It is no wonder the better physicians are leaving the province." "How can we make a diagnosis when we have to wait so long for test results? It's not fair to the patient." "Can you just imagine, there are about 2000 people waiting for major transplant surgery in Canada. Only about 200 are performed in a year."

Another major complaint revolves around their personal income which is slowly being eroded, not keeping in line with rises in the cost of living. I often hear, "we always have to seek a high volume of patients to cover expenses and make a living. It's not fair to the patient. We have no time to talk. And now they are putting caps on volume. Eventually we will have a three-day-a-week office." A family physician (non-GFT) told me,

> "Some patients want to die at home but families expect doctors to make home visits. Sometimes it takes a half hour to get to the home. I stay for fifteen minutes, and drive a half hour back to the office. I lose money on home visits. It's not fair."

Home visits are out of the question, except for the physicians at the CLSC who are on straight salary. Even then, it's difficult to reach them. They are extremely busy. Only by dialing 911 for Urgences Santé will you have access to a quick home visit - providing the nurse at the end of the line approves your request.

> "Quebec doctors are among the lowest paid in Canada and they want us to move to the countryside, otherwise we are penalized." "It costs me money to run an office. The day will soon come when a machine will answer my calls. I will then screen the urgency of the calls.
>
> "Rabbi, they are gradually and slowly cutting out payment for certain procedures. They blame *greedy doctors* and want us to do it practically free of charge. When I told the patient that I get four dollars for a cardiogram, he laughed and said, "a plumber gets more just as he

leaves his office to make a call".

> "Which profession in the world penalizes its members for wanting to work in cities rather than in rural areas? Rabbi, this is a communist concept, not a democratic one. Further, rural areas in the United States are invariably close to medical centers. In Canada, our population is centralized within one hundred miles from the border."

Surgeons complained about the lack of operating room time. There is a dire shortage of anesthesiologists. The waiting list for important surgery often stretches for two to three months. One surgeon told me, "Rabbi, I'm afraid to pick up the phone. It's depressing when you have to tell a patient who is in pain that he has to wait his turn."

Sometimes a patient in hospital tells me, "Rabbi, I'm waiting for heart surgery and I've been bumped for three days. It is nerve wracking." "It's almost as if all surgery today is on an emergency basis. Everything else is considered elective, placed on hold until an operating room is available." - is the complaint made by surgeons.

Shortages of beds also anger physicians and surgeons. This is where you find internal strife between departments. Which department gets the bed? Is it Surgery, Internal Medicine, Geriatrics, Orthopaedics, etc.? Almost ninety percent of our patients come through Emergency. Staff doctors resent this. "The only way I can get my patient in is through Emergency. There are no beds. Then I am at the mercy of Triage and the Gatekeepers."[47] Others see it differently. "Rabbi, our hospitals are being taken over by Geriatrics and the LTCs (long term care patients). This is supposed to be an acute care institution."

And although many of the physicians resent Emergency, I understand their

situation. Basically, the government has pressured Emergency departments to have all patients emptied from their areas in forty-eight hours. The pressures are immense. What happens when there is no place upstairs? What can be done for patients who cannot go home? How do we cope with our "suitcase patients", elderly persons who are dumped with a suitcase into Emergency areas because there is no one to care for them at home? And what happens when many patients arrive at one time, waiting rooms are jammed, people and families are frustrated and nervous and then families are told, "there is nothing we can do for your father. You must take him home." This is after a six hour wait in Emergency waiting rooms.[48] One Emergency doctor described what Emergency calls a "surge". This is when too many patients in Emergency need admittance. Floors are advised that solariums, conference rooms, and special holding areas will be opened up for patients. Some hospitals open the corridors. These are moments when staff can be overwhelmed throughout the hospital. Another Emergency doctor reminded me, "Do you recall the story of the lady that was raped last year and went to Emergency and was not seen by the doctor? The papers played it up. The doctor was vilified and almost described as cruel. But you know, the doctor was right. He had to see patients who were more ill. She could only be seen the next day when there was more staff."

Geriatrics is also a high stress area. In our hospital, the children of many Long-Term Care (LTC) patients resent moving their parents to LTC institutions which are not kosher.[49] They argue that their elderly parents have observed kashrut all of their lives and "now you want to send my parents to the Centre Hospitalier Côte-des-Neiges? It's

not right." The doctors argue in return, "but your mother does not need any more acute hospital care. It's not her place anymore. Besides, there are others in Emergency who need the bed more." The family replies testily to the doctor, "Tell me doctor, and if it was your mother, what would you do? Let's call the rabbi."[50]

Another complaint was expressed towards the specific language issue in Quebec. The province in general and hospitals in particular cannot attract good physicians or surgeons if they don't speak "the language". One surgeon said to me, "It's depressing. Many of our younger doctors are leaving. If I was younger, I wouldn't stay. They have taken the pleasure and joy I used to have out of my career. Rabbi, do you recall the episode of the lung transplants which were supposed to have been done only in a Quebec City hospital? They couldn't even attract the surgeons from Ontario - although they didn't have to know French - to do the operation. In the meantime, patients died in Montreal waiting for the operation."

No doubt there are physicians and surgeons who, for many reasons, would like to move to Montreal and work in our hospital. They are competent, some super competent. Credentials aren't the problem. They just can't be licensed because of the language issue. To quote a surgeon, "It's heart-breaking. They would be accepted anywhere in the world, but not here. We could even work out allowances for their children to go to English schools."

How do physicians cope with this stress? A candid excerpt from the biography written by David Hilfiger may shed some light,

> Nevertheless, physicians do deal with these stresses. We have found ways to continue practising in the face of this pressure. How do we

> respond? The language we use hints at the answer. We begin to learn to detach ourselves from the chaos of the situation. Mr. Smith with all his fears and insecurities becomes the *stroke in room eight*, thus allowing us to concentrate on his physical disability; Mrs. Jones, who regularly disrupts the office with her incessant demands, becomes *a problem patient* whom we manage with behaviour modification. We next learn the principles and productivity. *Patient management* is the buzzword and *productivity incentives* are standard practice at many large clinics to encourage greater efficiency in office and hospital. Then the physician discovers the protective coat of prestige and authority. When I told Mrs. Murphy that we had done everything we could to treat her husband's cardiac arrest, I was using the power of my position to close off questions, to protect myself from the implied criticisms. Any continued questioning would have been a direct challenge to me, a step only the most assertive sort of person might take. In addition, we physicians protect ourselves emotionally by keeping ourselves at the top of the medical hierarchy. How often is the physician *Dr. Hilfiger* while the nurse is *Mary Ann*? Finally, though no language hints at this, there is our wealth to comfort us. If we must suffer outrageous stress, at least, so the unspoken theory goes, we will be compensated financially.
>
> These responses, clinical detachment, efficiency and productivity, prestige and authority, hierarchy and wealth - are not intrinsic to the practice of medicine. Although the structure of modern medical practice may encourage them, we physicians also choose to endorse and accept them, in part as a way to relieve the inordinate pressure of our work. They seem to offer a kind of escape. Unfortunately, the escape is only illusory.[51]

Dr. Hilfiger seems to escape to a dream world. He detaches himself from the patient, almost blasphemous to the art of medicine. Then he learns some principles of efficiency and some popular phrases which promote productivity, all to impress his colleagues. Then comes the coat of authority to protect him from families who might question him, and then he uses his air of authority for nursing. Finally, he basks in his wealth. This is the "real" comfort. At least he is financially compensated. And although Dr. Hilfiger speaks as an American physician, perhaps many Canadian physicians cope in similar fashion.

There are many reasons, other than those I have mentioned above, which account for the physician's dissatisfaction. There has been erosion of physician autonomy, from complete control of their own diagnostic and therapeutic approaches, where and how to practice, how many patients to see, whom to charge and how much to charge; all this has been largely wiped out within the last forty years. The changes have been devastating to the older traditional doctors. They have just become another commodity in an open market. Now I hear words which were unthinkable a few years ago. "I hope my kids don't become doctors here in Canada. I hope they go into business. Anything but a doctor." Medicine is no longer an appealing career to many young people.

As we struggle with government intervention in terms of hospital cutbacks and physician buyouts, we can briefly look to the American system to understand the transformation and correlate it to our own. Once again, however, we must bring our focus back to ethics. For all these factors impinge on a physician's approach to ethics. It is difficult to talk about ethics to a group which feel they have been degraded and scapegoated for the many ills of a government.

First, despite many contrary arguments, medicine is becoming more standardized every day. Physicians are expected to react and treat patients within a standardized framework of procedures and time limits. It is becoming a fact of life. Any malpractice lawyer will testify to this.

Second, the physician does not work alone anymore. He is almost totally dependent on sophisticated expensive machinery and laboratories which have become partners in his decision process. The physician is then expected to enter into a specific

treatment mode. Patients and family can thus measure and can contradict the competence of a physician.[52]

Third, through computer programs and the internet, patients and families are more informed than ever before. There are web pages available from cancer, lung and heart associations, hospitals, health reference centers which offer one-stop shopping, medical schools, pharmaceutical companies, medical journals; all these and much more are available at all times to patients and families. Today a patient can visit a doctor and ask knowledgable questions. The physician may honestly answer, "I never heard of it." It is impossible for a busy physician to be up-to-date on the wealth of information pouring into the medical depository of knowledge.

Fourth, hospital administrators without any medical training have replaced physicians as Chief Executive Officers of hospitals. Their specialty training lies in the managerial practice which cuts spiralling costs to manageable levels. While physicians may be consulted, they do not have the last word. The impact is devastating. It is as if the physician is no longer a master in his own home. In fact, they now have to justify even minor decisions in relation to hospital guidelines set by administration. Jane Fulton emphasizes this but also puts the blame squarely upon the physicians. She writes,

> Prescribed policies have replaced individual professional opinion. Information systems analyze billing patterns, prescription patterns, surgical patterns, referral patterns, manpower distribution, and physicians' incomes. Data are available too and quite logically are used by all interested parties. Physicians in groups have, for decades, reduced the autonomy of individual physicians. Now consumer representatives or corporate representatives have been able to become part of the controlling mechanisms because physicians laid the ground work. The clock cannot be turned back now.
>
> At various points in history, physicians, as a group, developed

> medical care standards and made them mandatory. They controlled physician access to hospitals, used doctor profiles to alter physician habits and incomes, wrote policies governing the admission of patients to hospitals, described the training requirements for specialty status and, through their recommended fee schedules, estimated the relative value of various professional acts. In the evolution of policies in each of these areas, the decision-making process moved from reliance on opinion to reliance on data. Physicians, individually and collectively, should not have been surprised when other interested parties also began to use these same data for the same or for other purposes. When medical judgement was central to the decision-making, the physicians cornered the market. Now, individuals with data analysis skills have become able to intelligently favour certain choices because data show that one option is better than the other options.[53]

Fifth, many physicians feel trapped. The older doctor says, "If I were younger, I'd leave Quebec immediately. This is no place to practice medicine."[54] And although many younger physicians are leaving, others remain hesitant. They haven't a government guarantee for employment if they move to the United States. They have to do it on their own. Most physicians in the United States are dependent on insurance companies for their livelihood. These physicians need special staff just to fill out insurance claims. Thus, many feel bound and tied to these companies and hospitals. This inherently curtails any meaningful physician input to the system. Through following the rules, they are considered productive, otherwise they are expendable and released. After their contract expires, other physicians are hired.

The Canadian system may not be far behind the American way of thinking. The major difference between both systems at this time is that instead of insurance companies, we have government and hospital policy. In May 1998, the CMA issued a policy summary titled, "Physician Health and Well-Being". I quote at length from this policy summary because I note a sense of urgency towards many of the difficulties that

students, residents and physicians were having within the framework of our present medical system.

> Historically, physicians have encountered many professional and stress factors throughout their education, training and practice. Many of these are inevitable in this demanding profession. There are indications, however, that physician stress is on the rise; increasingly, medical students, residents and practising physicians are voicing distress and seeking assistance in coping with stresses in their training, practice and personal lives.
>
> Several recent developments may have negative impact on physician health and well-being. These include the rapid pace of change in the health care system, an unprecedented growth in medical knowledge and technology and the accompanying ethical dilemmas; the political and economic uncertainty affecting practice location remuneration; hospital closures and mergers; and the need and expectations of an increasingly informed public...
>
> Other stress factors are occupational in nature and are related to career choice, heavy workload, sleep deprivation, frequent on-call responsibilities, practice management and financial problems, and litigation issues and increasing expectations of patients and the public. Some of these stress factors faced by medical students and residents are common to many people; these include financial worries, strained relationships and social pressures. In addition, medical students and residents are challenged by a number of unique demands including long and intensive study in training that leave limited time for rest and personal activities. Students and residents also have reported stress arising from competition with peers, intimidation, abuse and harassment.
>
> Compounding these stress factors is an uncertain training environment. Todays medical students often feel pressured to make decisions about their career path as early as the second year of medical school. In addition, students face the relatively recent prospect of limited practice opportunities or unemployment upon completion of their training.[55]

The upshot of this policy is that the Canadian Medical Association issued sixty-five different recommendations aimed at governments, regional authorities, decision-makers in health care facilities, medical schools, faculty, undergraduate and postgraduate program directors, and those representing national, provincial, and territorial medical

organizations. In my estimation, this is an important move on the part of the Canadian Medical Association which only reflects the severe stresses medical students, residents and physicians are struggling to cope with at this time.

Many physicians presently envision the growth of a two-tiered medical system which would relieve pressure on governments, hospitals and physicians. For most patients, however, this could prove very difficult. Although our present situation has only produced a negative impact on the quality and accessibility of health care services, a two-tiered system could result in greater divisions between the rich and the poor. Families who could not afford the superior system would bankrupt themselves in order to be better served.

The transformation of the health care system has to be seen in its larger social and political context. Major cuts to welfare, employment insurance, pensions, legal aid and virtually all social programs have had a devastating impact, particularly on people of low incomes. In almost every sector, the government has disengaged itself, privatizing everything possible and shifting responsibilities to individuals, families and communities. In health care as in other areas, social policy decisions are being made solely according to financial considerations. A comprehensive vision of what we want as a society is sorely lacking.[56]

Summary

The purpose of this chapter has been to afford a fuller view of the present medical

situation in the province and how the major players - patients and their families, physicians and government - are coping with the situation. As we approach our physician and family interviews, we begin to note the psychosocial and political pressures that patients and their families, physicians and hospitals must deal with as they find their place in the system. We begin to get a better understanding of the whole picture and it is only after assessing and analyzing the whole situation that we begin to understand their individual approaches and views towards medical ethics and, specifically, towards end-of-life situations.

In the first section of this Chapter, I have tried to show that the capacity of physicians to deal with ethical issues has been diminished from their early medical education experiences through to hospital residency. The lack of any meaningful emphasis on medical ethics has taken a toll upon the physicians' human touch, their ability to grasp the art of medicine and to communicate in a trained and professional manner.

The second part of the chapter dealt with the pressures physicians face from government and hospital administration. Together with families, they are discovering that their options for treatments have been narrowed. They feel as if they are cornered into a niche which doesn't allow them very much room to manoeuvre. This has become, for them, an accepted fact of life. Ethics is rarely thought about in their daily practice.

From the view of the physicians, I have also noted a decline in their traditional power base. From the physician who established and inaugurated all medical hospital procedures, they have become just another player in the medical system. We have seen

how government has taken control of their authority, limiting their numbers within the patient population, forcing them to see more patients in order to earn their living while placing a cap on their financial income. We have witnessed the reduction of the amount of hospital admissions, cutting of staff and shortages in medical equipment and the long wait for testing procedures - all of which limit the professional responsibilities of physicians who are striving for a semblance of excellence in medical care. Further, government is even controlling the length of patient hospital stays and medical procedures that physicians are permitted to use. In the context of medical ethics in end of life issues, I thus propose a hypothesis that, because of the pressures placed upon them, "physicians will tend to see medical futility as a decision not to prolong death, allowing the patient to die and to get on treating those who are more treatable".

From the view of government and hospital administration, budgets and rising costs in medical expenditures are the primary concerns. From macro to micro decisions, governments are struggling to balance budgets. The result has been the development of the virage ambulatoire which is a move towards outpatient service and family care at home. The problem is: 1) patients are older and often geriatric, needing more hospital care; 2) families are not as cohesive, often separated on a social and physical plane and cannot take care of their loved ones; 3) outpatient services, day surgery, and CLSCs are woefully inadequate to cover the growing aging population and the caregivers who have received little or no training in the care of their bedridden patients. The results suggest another hypothesis in medical futility, namely, "government and hospital administation see medical futility as prolonging death and patients should be allowed to die so that

more treatable patients can be offered the use of the available beds."

I have not yet discussed the family. This will be dealt with in Chapter 5. I would assume that, at this point, the patient and family are caught in the squeeze between physician and government pressures. Perhaps they are like the wind-driven leaf that has yet to find a resting place. Patients do realize that life in the medical system requires an abundance of patience. They have to wait and wait in emergency rooms, for medical tests, bed openings, in doctor's offices and admittance to hospital. This has become a fact of life and they are embittered because of it. They have witnessed the medical care system - once a pride to our country and province - falling apart little by little. Perhaps the baby-boomer generation's concern over what will happen to them as they get older will save the day.

Notes

1. Edmund Pellegrino, "Teaching Medical Ethics: Some Persistent Questions and Some Responses", *Academic Medicine* 64 (Dec. 1987): 701-704.

2. Vladmir Dzadik, "Postgraduate Medical Ethics Education: Canadian Fellowship - Proposal and Practice", in Medical Ethics for Postgraduate Medical Students, Symposium 1990 Proceedings (London, Ontario: Westminster Institute for Ethics and Human Values), 66-70.

3. *Ibid.*, 67.

4. John R. Williams, Biomedical Ethics in Canada (Lewiston, New York: Edwin Mellan Press, 1986), 19.

5. François Baylis and Jocelyne Downie, "Ethics Education for Canadian Medical Students", *Academic Medicine* 66, no. 7 (July 1991): 413-414.

6. *Ibid.*, 414.

7. V. Sweeney, A. Browne and M. Brouds, "Results of the Survey on Undergraduate Ethics Education in Canadian Medical Schools", University of British Columbia, 1993.

8. Katalin J. Margittai, Rebeka Moscarello and Miriam F. Rossi, *Annals of the Royal College of Physicians and Surgeons* 27, no. 4 (June 1994): 204.

9. Henry K. Silver and Anita Duhl Glicken, "Medical Student Abuse, Incidence, Severity and Significance", *Journal of the American Medical Association* 263, no. 4 (January 26, 1990): 527-532.

10. Frederick Lowy, "The Ethical Professor of Medicine: Challenges for the Twenty-First Century" delivered in Jerusalem, Israel, January 1998, p. 4.

11. *Ibid.*, 16.

12. *Ibid.*, 17.

13. Frederick W. Hafferty and Ronald Franks, "The Hidden Curriculum, Ethics Teachings, and the Stucture of Medical Education", *Academic Medicine* 69, no. 11 (1994): 861-870.

14. Eric Horlick and Gerry Dankoff, "The Most Important Thing to Remember is... What I Didn't Learn in Medical School", *PULSE*, the Sir Mortimer B. Davis Hospital Staff Newsletter, March 2000, p. 2.

15. Glenn McGee, "Phronesis in Clinical Ethics", *Journal of Theoretical Medicine* 17 (1996): 317-328.

16. *Ibid.*, 317-318.

17. *Ibid.*, 326.

18. M. Yeo, "Primum Non Nocere: The Ethics of Teaching Medical Ethics", *Teaching Philosophy* 12, no. 1 (1989): 23-24.

19. Herbert Ho Ping Kong, Peter A. Singer, Abbyann Lynch and Mark Siegler, "Symposium: Teaching and Learning Clinical Medical Ethics during Residency Training", *Annals of the Royal College of Physicians and Surgeons of Canada* 21, no. 6 (1988): 423-426.

Symposium 1990 Proceedings, Medical Ethics for Post-Graduate Students (London, Ontario: Westminster Institute for Ethics and Human Values, 1990).

Jean Desjardins, Sister Nuella Kenny, Abbyann Lynch, Gordon L. Crelinstin, Frédérick Grunberg, John Watts and John Ruedy, "Symposium: Teaching of Biomedical Ethics in Post-Graduate Training Programs", *Annals of the Royal College of Physicians and Surgeons of Canada* 25, no. 5 (1992): 309-312.

20. The Royal College of Physicians and Surgeons of Canada, General Standards of Accreditation (May 1989), 1-15.

21. David Barnard and K. Danner Clouser, "Teaching Medical Ethics in its Context: Penn State College of Medicine", *Academic Medicine* 64 (1984): 745.

22. See issue of *Academic Medicine* 64, no. 12 (December 1989) which is devoted to teaching medical ethics in American universities.

23. T. Douglas Kinsella, "Curricular and Remedial Targets in Post-Graduate Medical Ethics Education in Canada" (London, Ontario: Westminster Institute for Ethics and Human Values, 1990), 36.

24. William Osler in an address delivered to the New York Academy of Medicine in 1902 as quoted by Mark Siegler in "Symposium: Teaching and Learning Clinical Medical Ethics during Residency Training", *Annals of the Royal College of Physicians and Surgeons of Canada*, p. 425.

25. A "slow" Code is like going through the motions, not trying hard to resuscitate.

26. Herbert Ho Ping Kong and others, 423.

27. *Ibid.*, 423.

28. Laura Weiss-Lane, "Residency Ethics Training in the United States: Special Considerations and Early Experience in Medical Ethics for Post-Graduate Medical Students" (London, Ontario: Westminster Institute for Ethics and Human Values, 1990), 25.

29. Eric H. Loewy, "Teaching Medical Ethics: Is it a Waste of Time?" *Cambridge Quarterly of Health Care Ethics* 3 (1994): 297.

30. Laura Weiss-Lane, 22.

31. A. R. Jonsen, M. Siegler and W. J. Winslade. Third edition (New York: McMillan Co., 1992).

32. Laura Weiss-Lane, "Residency Ethics Training in the United States: Special Considerations and Early Experience", *Medical Ethics for Postgraduate Medical Students* (London, Ontario: Westminister Institute for Ethics and Human Values, 1990), 22.

33. Robert J. Levine, "Some Reflections on Postgraduate Medical Ethics Education", *Medical Ethics for Postgraduate Students* (London, Ontario: Westminster Institute for Ethics and Human Values, 1990), 47.

34. Some use the term "depend upon" instead of "fear".

35. *PULSE*, March 2000, p.2.

36. See Pat Armstrong and Hugh Armstrong, Wasting Away: The Undermining of Canadian Health Care (Don Mills, Ontario: Oxford University Press, 1996), 51-93. Much of my assessment of government and hospital strategies in health care is taken from this book. Their views correspond with my own observations and research.

37. Jeff Heinrich, "Doctors refuse work after hitting patient limits", *Montreal Gazette*, 12 May 1998, A1-A2.

38. Pat Armstrong and Hugh Armstrong, 67. Although the Armstrongs refer to this as the medical model, we will also refer to it as the administrative model because of the pressures physicians face from administration.

39. W.S. Rowe, I.M. Dulka, C. Pepler and Mark Y. Yaffe. "Discharge Planning Organization and Outcomes for Short Stay and Same Day Surgery Patients Aged 55 and Over: A Descriptive Exploratory Study", McGill University, The Centre for Applied Family Studies (November 1997).

40. Pat Armstrong and Hugh Armstrong, 74. These instances are recorded in a special hotline set up by the Ontario Council of Hospital Unions. People phone in telling of their experiences. Even if these personal experiences are exaggerated, it is still symptomatic of our "quick-fix" system.

41. Pat Armstrong and Hugh Armstrong, 73. One of the better hospital clinics is the Herzl Clinic in our hospital which addresses many of these issues. But the battle remains. Too many older patients, too little time, too little money, too little staff, too little access to tests and too long waiting lists are still a problem.

42. HMRI (Hospital Medical Records Institute) Comparative Analysis of the HMRI Database (Don Mills: HMRI, 1992), 1. The HMRI is now part of the Canadian Institute for Health Information (CIHI).

43. Armstrong and Armstrong, 84-85.

44. Stephen Lewis, "Another Day, Another Variation: When is Enough Enough?", *The Canadian Medical Association Journal* (Jan. 13, 1998): 61.

45. A. R. Jonsen, "The End of Medical Ethics", *Journal of the American Geriatric Society* 40 (1992): 394.

46. Emergency testing is available within days and even hours. But it adds to the backlog of others waiting who are bumped.

47. Triage refers to the selection of emergency patients for immediate admittance. Gatekeepers are the doctors who decide who goes up to the floor and who must leave the hospital from the floors.

48. Our hospital has a "state of the art" Emergency area which was finished in 1997 at a cost of over five million dollars. It was designed to handle 108 patients a day - we are now up to 145. Fifty-five patients are daily brought in by stretcher, which compares to twenty in other hospitals. This is because of the demographics in the Jewish community of which a large percentage is in the elderly population group.

49. Kosher or Kashrut involves special dietary restrictions which are quite complex. Large institutions such as hospitals which follow Kashrut regulations have separate "meat and milk" kitchens which separate the preparation of meat and dairy meals. It is quite complicated and needs special rabbinical supervision to be certified as a "kosher" institution. For further references on Kashrut see "Dietary Laws", Encyclopedia Judaica (Jerusalem, Israel: Keter Publishing, 1972), 6: 26-46.

50. In our Jewish community, we have three major long-term hospitals and nursing homes sponsored by the Jewish Community Federation. They total about six hundred beds. The waiting list in each institution is up to three years. There are some smaller private nursing homes with facilities for another three hundred beds. Most families prefer the community's long-term care institutions.

51. As quoted in Juanne Nancarrow Clark, Health, Illness, and Medicine in Canada (Don Mills, Ontario: Oxford University Press, 1996), 280.

52. John L. Graner, "The Primary Care Crisis, Part III: The Degradation of the Modern Physician from Artist to Labourer", *Humane Medicine* 3 (August 1991): 192.

53. Jane Fulton, Canada's Health Care System: Bordering on the Possible (New York: Faulkner and Gray Publishing, 1993), 72-73.

54. Eva Ryten, A. Dianne Thurber and Linda Burke. "The Class of 1989 and Physician Supply in Canada", *Canadian Medical Association Journal* 158 (1998): 7.

55. CMA Policy Summary, "Physician Health and Well-Being", *Canadian Medical Association Journal* (May 5, 1998): 1191-92.

56. From a document titled Health Care Alert, prepared by Project Genesis for the Council on Services to Seniors Advocacy Committee of Federation C.J.A., Montreal, Quebec. (December 1997), 1.

CHAPTER IV

THE PHYSICIAN AND FUTILITY

In this Chapter, I will briefly review the major definitions and elements of futility from the eyes of the physician. Notwithstanding the risk of being repetitive, I consider it important as we approach the physicians' interviews and how they initially understand medical futility. I will then examine how the doctors respond in futile situations and how their methods of coping fit into the four models I outlined in Chapter I. These were categorized as stressing: 1) physician rights; 2) family rights; 3) justice, including allocation of resources and fairness of government policy; and 4) better communication between physician - family and patient.

Next I will endeavour to assess and analyze the physician responses. I will examine their approaches according to their different specialties, communicative abilities, and personal historical views of the practice of medicine. I will then evaluate their responses and offer a critique of their views of futility based on the literature and personal experience.

Definitions of Futility

There are many definitions of futility.[1] [2] [3] [4] [5]

As mentioned earlier[6], there are two major definitions which seem to have left their mark on any accepted definitive approach to futility. The first stems from Schneiderman and Jecker's consideration of differentiating between treatment and cure. Physicians feel that their role is to improve or maintain health and if the treatment does not do this, it is considered futile. Secondly, there is a difference between viewing a body which may be alive versus the person who is not alive. The goal of medicine is to provide assistance to the patient as "person". Further treatment is unwarranted if there is no hope of improving the quality of life or the personhood of the patient.

Because of these considerations, Schneiderman and Jecker have divided futility into two components - the quantitative and qualitative aspects - and have defined each of them. From the quantitative view, they suggest, "when physicians conclude either through personal experience, experiences shared with colleagues, or considerations of published empirical data that in the last hundred cases a medical treatment has been useless, they should regard that treatment as futile".[7] The qualitative aspect suggests that "physicians should distinguish between an effect which is limited to some part of the patient's body, and a benefit which the patient has the capacity to appreciate and which improves the patient as a whole".[8] A treatment which produces an effect but does not provide a benefit is deemed futile.

The Task Force on Ethics of the Society of Critical Care Medicine has suggested another approach which distinguishes physiological futility from non-physiological medical futility.[9] Physiological futility is when the patient will not improve physiologically with the intervention. The treatment is futile because it will not achieve

its physiologic objective. Many ethicists, including R.D. Truog[10], argue that only physiological futility has validity because it is the only choice which is value-free[11] since it does not achieve any meaningful goals and there is no purpose to maintaining treatment. Non-physiological futility is when the physician decides "it's not worth it". In this sense, it is similar to Schneiderman and Jecker's qualitative approach except that it has a broader view encompassing many outside issues such as the use of scarce resources. Schneiderman and Jecker separate futility and rationing on the basis that futility is patient-based while rationing scarce resources stems from a societal decision to limit individual access in order to save money. This makes it an ethical issue of distributive justice, not futility.[12]

The underlying base for the physician's argument in the futility debate stems from what Brody calls the Principle of Professional Integrity. If the physician is forced to provide treatments that are futile, this would violate the dictates of the profession.[13] [14] [15]

In summary, I noted that definitions of futility are unclear, often overlapping each other. I also noted that futility can be a personal concept; what is futile to one is not futile to another. Indeed, declarations of futility can be value-laden and, therefore, a very complex issue.

Physician Interviews

At the outset of my study, five basic questions were asked of the hospital physicians:

1. Do you recommend a specific approach or style in giving the "bad news" (futility of further treatment) to the patient or family?

2. To whom do you give the news first - patient or family?

3. Do you believe families have the right to demand treatment even when it is inappropriate, or it is only the decision of the doctor?

4. If a family disagrees with you in a futile situation, how do you respond?

5. If there is an impasse, who should have the final say?

As the study progressed, I came to realize that physicians found a different response from Jewish patients and families than from non-Jewish patients and families. This led me to another hypothesis that Jewish patients and families are more aggressive in their approach to illness and issues of futility than non-Jewish patients.

As I note, the first two questions open up the communication process. The physician or surgeon must now approach the patient or family with the news. The family waits outside the operating rooms anxiously peeking in for a sign of the surgeon who has just operated on the patient. Or the family and patient is in the hospital room waiting anxiously for days to hear from the physician the results of the tests. "No news yet", explains the resident on a daily basis. The family is very anxious. The patient may not have slept in a few days. Finally, the doctor comes into the room. He looks at the anxious faces. "Rabbi, this is the most difficult part of it all. How do you tell the family who have such hopes? How do you break the news?"

In my discussion of the interviews, I will first look at how the physicians answered the first two questions. My purpose is to see if there are different approaches to communicating futility to families and patients. I also wish to note their comfort level

and the position of the family on the communicative level. After examining these questions, I will then turn to the next three, noting how physicians respond and communicate their feelings when families suggest inappropriate treatment in the futile situation.

Dr. A, from Surgery, offers the classic answer. "You have to tell them the whole truth. If not, you are caught communicating a lie. It's best to tell the truth. Besides, sometimes, they have to put things in order, financially and family-wise. It's difficult at first but in the end the patients appreciate it. The family is told only with the patient's approval. This, usually, is not a problem." This approach is representative of the major part of the literature. All patients are told the whole truth and have the option to involve the family or whomever they wish. The patient now becomes the major decision-maker and advises with the medical team. But it isn't that easy. Many physicians, if not most, in our hospital have a different approach.

A prominent oncologist, Dr. B, expresses it as follows: "Each patient and family is different. You have to feel your way around. In all situations, never be blunt. It is impossible for a person to survive with only bad news. You must leave a patient with hope." I asked him, "How can it be possible to do this in all situations?" He replied, "We focus on symptoms. We focus on options. We focus on what the patient wants to do. We try to help the patients work at doing their own thing. Make it as easy as possible for them. Work at the medication together. We break down patients into three groups. Seventy-five percent can cope with the truth. They begin living in two realities. It's most difficult and sometimes they deny it. I can understand it, to deny and go on

with hope. As things become more difficult, they begin to shift towards reality. A second group, about 15%, deny it completely and live in denial fighting to the end, never coming to terms. About 10% become completely paralyzed, incapacitated, dying in almost a suicical mode, always upsetting the family."

"Jewish families are protective. They tell us, *don't tell the patient.* But as I see it, our role is an act of love if you do it in a caring way. In Judaism there is a concept of *Baschert* (fatalistic approach - God wanted it this way). But this is complicated because at the same time they want everything done. I had a case of a gentleman scholar. Total reality was left behind. It was sad for the patient. I even helped the families get a second opinion and third opinion rather than make them travel. We show families that no stone is left unturned... If you're good to the family, the mourning process is easier."

Dr. B, like Dr. A, believes that the patients must be told. But not all patients; as he pointed out, "you have to know the patient and family. It's not a universal concept." He also talked about leaving the patient with hope. The first doctor, A, did not preclude hope, but he was more detached from the patient. He did not emphasize working within the framework of the patient's wishes. It was as if he was more mechanical in his approach, whereas Dr. B. was more empathetic to the patient's situation.

A third approach was taken by Dr. C from Internal Medicine. Dr. C is a gentleman in his sixties, considered to be a wise older physician - a father image to many physicians with a world of experience. He was a little sarcastic and even angry at the

questions. "Rabbi, you talk of communication. We haven't got the time anymore. There is no time to communicate. Forget about the old days. Of course you must communicate with families, but to do it properly takes time. Further, the family, including the patient, does not understand what we are talking about. The doctor says, *I told the patient one thing*. The family says, *the patient told us differently*. We give the patient good treatment but there is no time to talk. Sometimes I draw pictures to explain. I give them the notes telling them what to do. Fifty percent understand and 50% do not understand - even with the notes."

The doctor then veered the conversation to the difference between the American and Canadian health systems. He told of the following case: "A lady was in a car accident. She came to me after a few days and wanted x-rays taken. I took x-rays of her lungs and found a cancer. I asked her, *Have you taken x-rays of your lungs recently?. Yes*, she said, *a few weeks ago, but I don't know the results. They haven't phoned me yet.* I immediately phoned the other hospital. They advised me, *yes, we have taken the x-rays, but they haven't been read yet by the doctor.*"

"Rabbi, this happens every day. In the U.S. you get the results the same day because you pay for it, but not in Canada. Here we have to wait, and then the doctor said sarcastically, *perhaps it would be different if the attending doctor in that other hospital was ill himself.*"

Dr. D, a general practitioner, was more emphatic about the lack of communication. "Your question is unfair. We doctors are struggling to make a living at this time. Who has the time to speak to patients and families?" I asked him, "And

so how do you manage without decent communication?" He replied with another question, "Why don't you ask the GFTs (geographic full-time physicians who have their offices in the hospital) about communication? They have the time. We, who work from without the hospital, have no time. Our patients go through Emergency and then it is out of our hands."

Dr. D was quite bitter, not with me, rather towards the system. He continued, "We have become second-class citizens. I have very little communication with the staff physicians. But I must tell you that I do communicate well with the older Jewish patients. I speak their language. This, in itself, secures a connection and trust."

I did not get much from Dr. D, but he did bring my attention to the importance of simply speaking the mother-tongue of the patients.

Dr. E is a young lady physician in Geriatric Medicine. My first two questions were handled easy. "When you deliver sad news, you have to pick an area in which to sit down and explain the situation to the family. It should not be in a hallway. The physician has to be clear and allow time for all questions. Time is the key. I hardly have problems with families. You have to be compassionate. It is very rare that I do not find understanding and agreement from the family."

Dr. E shared a story of a dying gentleman. She had meetings with his wife, who was in complete agreement with a palliative care approach and understood the situation. When a daughter arrived from England, the situation changed completely. The daughter was an angry young lady, very disagreeable, insisting on seeing the chart and claiming that everything was not being done for her father. By now, mother slipped into the

background and Dr. E was only answering to the daughter. "In the end, the case did not work out well at all. The bitterness developed between the hospital ward and daughter. I found communication most difficult. What hurt me most was that the daughter and mother did not communicate. There was constant friction caused by a symbiotic relationship. What I learned most from this episode is the following: 1) Don't talk to different members of the family separately. 2) The physician must find out who the person of authority is in the family. 3) If there is friction in the family, throw all decisions back to the family and let them decide."

Dr. E seems to be an excellent communicator. She is patient and has the capacity to listen. She talked about the giving of time as an important element in communication. This may explain the frustration of physicians who talk about rationing time. Physicians must then depend on playing the dominant role as the physician who has no time to communicate with patient or family. This may be meant to reinforce the image of the busy, important physician, who has little time for *bothersome* patients.

Dr. F is an older surgeon in his early sixties, highly respected among the staff and colleagues. He insisted that you only tell the whole truth to the families, not to the patients. "Perhaps it's legally necessary to advise the patient, but, in my opinion and experience, it is not morally right. Further, patients hardly ever want to hear the whole truth." He told of an episode he had experienced many years ago. "When I was young, I took over the surgical practice of a brilliant and popular abdominal surgeon. The deceased surgeon, Dr. X, died at the age of 45 and left a thriving practice in my lap. On my first day, seeing one of his patients, I met a Jewish gentleman who had been

operated 15 years earlier by Dr. X. I read through the chart and said, *Mr. A, for a patient with a 15 year history of cancer, you have done very well.* The gentleman, who was standing, collapsed in a chair. *Who told you I had cancer? Dr. X never mentioned it. Are you sure? My God, this is terrible. I can't believe it.* Rabbi, this taught me a lesson. Dr. X was right. You should tell the family, but not the patient. If the family wishes, they can communicate it to the patient and then the patient can ask me. If the patient insists, which is very seldom, I tell him/her as they leave the hospital to go home."

A similar approach was expressed to me by Dr. G, another highly respected surgeon, who is often in demand by other surgeons for advice. He is also known for his gentleness, soft voice and caring attitude. He explained, "You have to know the family. Keep things comfortable. Give them hope. One never knows everything 100%. Even if the prognosis is bad, tell the family that we are not absolutely sure. Make it close to the truth. Do not be so definite. As for the patient, never tell everything. When you tell a patient the truth, you leave him nothing. Besides, he really doesn't want to know the bad news. Even when you offer the truth, they supress it. Tell him/her just enough. I know this is paternalistic, but our objective is to give comfort to the patient and to the family. I also realize that this is not a popular concept, but physicians are human beings. We are sensitive. Let me tell you a story. I operated on a kid who was in undergraduate school at McGill. He was from the West Indies, a fine young man. He had cholongial carcinoma. It was touch and go, a 50-50 chance he would make it. I didn't know how to approach the young man or his family after the operation. I sat with

the family, stumbled and stammered some words. *What do you think I should tell your son?* The father put his hands on my shoulders and said, *Doctor, this is my responsibility. This is not your area.* Rabbi, I almost died from embarrassment. I wanted to hide. So you see, we don't have absolute answers in every case. There are different approaches for every family, cultural responses that often differ."

After I left the interview with Dr. G, I was reminded of a similar story given to me by Dr. B., mentioned above. In this case, the doctor found himself being supported by a family. "How unprofessional it was. I wanted to run." I really did not understand the reactions of both physicians until it dawned upon me. They were both saying, "I'm supposed to be the doctor. I'm supposed to be in control. I'm the one who gives advice, medication, operates upon, and cares for people. Look at me now. I've been exposed. I'm so vulnerable as a human, so failing. My own patients and their families are supportive of me. I wanted to run and hide."

What does all this mean? First, doctors believe that they must be in charge of the situation. This is reflected by the patient who comes to them seeking medical assistance. With every visit, the attitude of patients and families reinforces the authoritative role of the physician. Second, when the physician suddenly finds himself exposed and unmasked, he/she is no different from most human beings who in similar situations would wish to run and hide. Third, the families and patients have placed the physician in an exalted position which they are forced to maintain. If they were to lower the prominence of this position, physicians will have lost their stature as the wise competent doctor. Perhaps, what we are saying is not profound, but the implications

are important in the futile situation. The physician still wants to maintain control. Despite his inability to save this life, he still wants to remain a significant figure who controls the situation. This is in contrast with Zawacki, who suggests physicians take a more human and open approach, an understanding of mutual vulnerability and level of transparency. This latter approach is in order to activate an "I - thou" relationship between physician and patient.[16] But even with Drs. G and B's need to express control over the situation, one still senses the fresh breath of humility. Within their responses, Dr. G emphasized, "we are never 100% sure", as if to say "we make mistakes". Dr. B went along with his patient's desire to try a questionable cure. Recall his words, "I help patients get second and third opinions when the prognosis is not good." Indeed, the present physician-centred termination of treatment in futile situations has a potential for abusive power. If the physician is permitted to make value judgement decisions concerning futility, this in itself creates an opening for the abuse of power.

Dr. H is a physician in Pulmonary Medicine. He approaches the futility issue with great caution. "Before speaking to anyone, try to find out the relationship of the patient to the family and the family to the patient. Invariably, physicians will always speak to the family and often find themselves in collusion to keep the patient protected from the bad news. Theoretically, a patient comes first. In practice, the physician has to know to make sure the patient is ready to hear the news. Timing is most important. So the whole situation is quite delicate. Sometimes you talk around the situation, sometimes it is easy, other times it is very difficult."

Dr. I, a prominent obstetrician/gynecologist, also claims that telling the patient

or families can be very difficult, confusing and quite demanding. "Jewish patients and families are tough. Families want to hide the diagnosis from the patient. Sometimes professionals find it difficult to talk to patients and family. On the other hand, the patient, most of the time, does not want to discuss it. The key is the doctor. He has to lead the communication between patient and family. Be honest and never take away hope. ... Start talking to the patient about his illness. The patient may change the subject. He/she will let you know when they are ready. Second opinions are very important. It can resolve the conflict. A major problem is that the physician/patient relationship is being eroded when patients are sent home earlier. The doctor sometimes hardly has time to speak to the patient." This is similar to the position of Dr. G, who also spoke of the deterioration of the doctor/patient relationship due to the technological changes in medicine. Dr. I continued, "There is no simple one-on-one relationship anymore. Too many doctors now become involved. For example, a patient goes to ER (Emergency Room), where he sees one physician. He is then sent upstairs for a test and an x-ray. This may involve two more doctors. The patient asks questions. They are reluctant to give answers. Your doctor in Emergency will tell you what the results are." When the patient returns to Emergency, a new shift of doctors has begun. The patient doesn't really know with whom to communicate." Dr. I emphasized "Rabbi, you have to develop a relationship. I give time to my patients. Then you send them to consultants."

Dr. J, a senior physician in Pulmonary Medicine, speaks to the family within a framework of a few rules: "1) Don't give out the bad news at one time. Say *We are not*

certain of the diagnosis yet, but it's tough. 2) Try to find reassuring factors in each case. Emphasize these factors, e.g., *It's not all bad. We have new methods of treatment.* 3) Families know best how to break it to the patient. You have to listen to families, but you have to say what's on your mind and have an honest dialogue. With Jewish families, you will be dealing with guilt. You have to steer them back to what's best for the patient."

Dr. K, one of our palliative care physicians, also follows the cautious route. We hear, "not all patients can cope with death. Information has to be given piece-meal; only then can you see how the patient handles the news. Jewish families always want to know every detail, but their decisions have little to do with the knowledge received. Decisions are connected to family values. They always hide the truth from the patient. It's difficult to communicate in general in palliative care. We deal with anger, hostility, depression, and what families consider abandonment."

Dr. L, a former physician who is devoting his time to research, discussed my research questions over a lunch. He explained, "I witnessed many changes in medical practice and I know most of the doctors here. I think it's a trade-off - good communication for better medicine. But it's not mutually exclusive. Years ago, family practitioners felt at home in the hospital. You could communicate with your own doctor. Now it's all GFTs, but as medicine became specialized, isn't it better that we have GFTs to look at complex problems? And the personal part is not lost. Rabbi, you know our doctors. They agonize over patients. They are doctors who care. On our CTUs (clinical teaching units) each specialist spends about 18 days or a whole month on the

ward and they are damn good. And they are good with patients as well."

Dr. M is from Family Medicine. His style encompasses the "good" and "bad" news approach. "You speak to the patient. First you tell them the bad news. He has a tumour which could be fatal. The good news is that it can be treated. Rabbi, everybody has a fear of death. In olden days, people died at home with families surrounding them. Today, in our youth worshipping society, no body wants to die at home. Families choose the hospital. This is wrong. The hospital is not the place to die. It's so impersonal."

Interpretation of the Physicians' Views

Dr. M has touched upon a crucial theme. How does our society view illness and death? How do individuals facing terminal illness and their families view death? There may be a difference. A youth-oriented society sees death as the "enemy". It belongs to the realm of the elderly and infirm. Younger people cannot identify with illness, death and the elderly. It is something remote from their thoughts. In fact, younger persons may feel resentful about the higher medical costs and pensions for older and unproductive individuals. And so we have a dichotomy. On one hand, older patients belong in the hospital, not at home, because society tells us this is where older people belong. On the other hand, it is too expensive to keep them in hospital. It is not fair for society to carry the burden. The result is that when futility is invoked, it is the physician who should be in charge to decide if continued treatment is futile.

From the patients' and families' view, they would argue that they have paid their taxes and contributed to the health care system for years. It is now payback time. "Society owes it to us. It is not fair to deprive us of our rights." From this vantage, the family may have more input into the decisions of futility claiming that at the very least they are on equal footing with the physician in the futility debate.

Physicians, too, may experience an ambivalence towards death. In addition to personal family experiences which may cause the physician to be uncomfortable facing end of life decisions, there is the general battle between medicine and death. Physicians are supposed to save the patient from death. Phillipe Ariès describes a paradox.[17] In previous years, death took place at home. It was a natural event. Families would surround the patient and death was an accepted passage of time. In our modern era, we die in hospitals because we expect to be saved and now that we live longer, we fear death. Our language in hospitals implies that a battle is taking place. People don't just die, "they lost the fight". Doctors describe how "they lost the race". "Time to give up". "The patient succumbed". "The patient gave up." It is as if it was the patient's fault that the battle was lost. Callahan explains the situation from another view.

> At the heart of modern medical enterprise, there is a profound ambivalence about death. It pits clinical medicine which must accept death, against research medicine, which refuses to accept any of the causes of death. Research medicine carries on an all-out war against death, but it is a war that has harmful consequences for clinical medicine and patient expectations. Some greater degree of peace must mark the encounter of death and medicine. Since death comes to all human beings, and since science has no reason to believe that death can be cured, death can not and should not be seen as the ultimate enemy of medicine. Medicine should help us live better with our mortality.[18]

Within the framework of either Ariès' or Callahan's view, the result is that

physicians are at war. Sadly, it is a war that medicine will always lose. The clinician is caught in the middle. And as Callahan says, "the image and metaphor of war is not the appropriate one. If we think of it as war, death will always win. Always."[19] It is perhaps this image of a losing war which causes physicians to abandon patients. It may also be a way of thinking about futility. The physician says, "we can't win. Let's cut our losses and let the patient die." It may also explain why physicians seldom attend the funerals of their patients. It reflects their inability to face a family after losing the battle.

I am reminded of an interview I had with Mr. Sam Cohen, our hospital's first Executive Director. Mr. Cohen seemed to be more pragmatic. "Rabbi, in older times, people didn't want to go to hospitals. We knew that when a patient had pneumonia or a serious infection, there was a 50-50 chance of survival. There were no antibiotics. The body had to battle it alone. Families, especially Jewish families, visiting a patient in an oxygen tent, knew it was a matter of days. There was anger and weeping. The patient knew it was the end. There were horrible scenes. The result was that patient and family avoided the hospital like a plague. Today it's different. We can cure. We have the technology to prolong life. No more is it certain death. So people flock to hospitals. They want to die in a hospital setting when they can say that everything was done."

Mr. Cohen continues, "But this is slowly changing again. Our Jewish people have now learned to accept death. We hardly see the wailing and breast-beating anymore. We have acculturated to the general population's view. Death is a normal process. It is a passage from one stage to another. However, this comes slowly and

often at a terrible price. We still seek second and third opinions. Many of us spend fortunes moving heaven and earth to save a family member.[20] Accepting death does not mean giving up life. We will fight like hell to save a life. It's still the highest *mitzvah* (most important commandment)."

Unlike Dr. M, who views the hospital patient population from a youth-oriented society, Mr. Cohen is more simple, pragmatic. Sociopolitical issues are not important. He sees the hospital as the place to die because everything is being done to save a life. One cannot do this at home. The result, however, now pressures the physician to do everything possible for the patient. In cases of futility, when the doctor says to the family, "We are prolonging death, not life," many families will find this difficult to swallow because illness is not to be associated with death, but with our responsibilities and duties to save a life. The major comfort for the family is the knowledge that everything was done. "We tried everything." Once again, the family becomes aware of the process which, although it had a sad ending, brought a sense of satisfaction to the family because of the efforts of all involved. Personally, I have had the pleasure to work with Dr. Benjamin Freedman, who was our Clinical Ethicist, and unfortunately died at the young age of 47. He used to argue that in the Jewish family it's just not a matter of ethics, but it's an ethic of duty stemming from the fifth commandment of honouring parents. This is why Jewish families always connect a strong sense of duty towards their relationships to family members.[21]

Summary

What we have seen from the physicians thus far are different notions about dealing with futility. In the medically futile situation, does telling the truth to patients and families require the whole truth, something close to the truth, or various forms of information which evade the truth? Telling the truth is obviously not an easy task as we confront patients and families with bad news. Some of the doctors felt that nothing but the whole truth was the proper approach, while others communicated half-truths which could be misleading. Some withheld vital information while others tempered the truth by evading hurtful details. It was as if they walk a tight rope, do a balancing act as they approach the patient and family at this most difficult period. They don't know what to expect. We would like to have patient participation and discussion, but as the physicians pointed out, the patients have to be ready to hear the news, to absorb it and to work it out. In the end, it is close to a judgement call about what could be most helpful to all concerned or could cause serious repercussions which could end any further meaningful communication. We may hear, "How dare the doctor tell my mother that she has cancer?" Or, "The doctor was a gem. He knew exactly how to talk to the patient, not telling her the whole truth." Or, "The doctor told it how it was. He explained and told us the honest truth. We are very grateful." As we have seen with our physicians, most took the middle road.

While terms of not taking away hope and being realistic may sharply contrast, nevertheless, we are dealing with patient and family expectations to cure and be cured.

A middle approach is difficult under these circumstances. This all-or-none approach may be inter-connected with a Jewish cultural response from physicians and families. Life is to be stressed at all costs - except for a life of pain. An in-between middle ground, where one is encouraged to find different hopes, is not easily accepted. Coming to terms, acceptance, or finding a space in-between hope and reality is possible and even advisable, but very difficult for Jewish patients and families. We shall see more of this as we develop our family interviews.

How Physicians Deal with Families in Futile Situations

To this point, I have endeavoured to uncover the physician's concepts, responses, patterns and styles in communicating with patients and family at the start of the futile situation. I now turn to my last three questions which involve their responses when they are on a collision course with the family. The physician now says, "The patient is dying. It is futile to continue with any sort of treatment, resuscitation, feeding, etc. It is now time to keep the patient comfortable in a palliative care mode or at home." The family, in return, claims, "We have to continue trying. We will not give up. We must continue to treat him aggressively. Doctors make mistakes too and his time will come when the good Lord takes him."

I am reminded of an encounter which I had upon my arrival as Chaplain in our hospital approximately twenty years ago. A surgeon took me aside and said, "Let me give you a piece of advice which has become a humorous anecdote. Nobody dies a

natural death at the Jewish. Everyone dies only because of neglect or mistakes. It's the surgeon's fault, the resident who came too late, the nurses who were on break when it happened, the orderly who never shows up on time, the physician who gave the wrong prescription and the original misdiagnosis in Emergency. Rabbi, it's always the fault of the staff. So be prepared for the onslaught and discount three-quarters of what you hear."

It was sage advice. I never forgot it because I felt, many times, it was on the mark. Our physicians are caring, our nurses are exceptionally well trained, and we are generally proud of our hospital. I often see nurses and doctors extend their shift up to an extra hour without pay. No doubt some people slip through the safety net. There are cracks in the system, as I have mentioned. But if family involvement and concern can be measured, it is most notably seen by the numbers of family members sleeping in the hospital waiting rooms. They bring pillows and blankets and we have over a dozen or more cots which are placed in the patients' rooms upon request. These cots are at a premium. It is hard to find one that is not in use. On many occasions I have given my office to family members who wish to sleep over. This is a reflection of the ties between family and patient.

In response to the family-doctor collision course, Dr. A pointed to the hospital policy and procedures concerning final decisions about resuscitation and other critical interventions.

The policy was quite clear to Dr. A. It read that in certain instances of futility, intubation, resuscitation and transfusion do not have to be attempted, initiated, or if

initiated, continued. The physician must rely on clear medical evidence and documented consultation which supports his/her views. The patient is given the opportunity to seek further medical opinion and if the disagreement continues, the Ethics Committee becomes involved. If the Ethics Committee agrees with the attending physician, the patient should be notified. If the Committee does not agree with the attending physician, the patient should be assigned another physician. If the patient or family disagrees with the Committee's decision, then the hospital should seek a transfer of the patient. We read from the policy,

> The conclusion of this meeting does not conclude the hospital's involvement in these cases. Appropriate hospital resources must be made available to assist the patient and/or family in the grieving process. The patient and/or family will be informed that the hospital will make every attempt to transfer the patient, if the patient so desires. If another facility has expressed its willingness to accept the patient for care within a reasonable time period, and the patient and/or the patient's family desires transfer, the hospital must facilitate the transfer which will be accomplished at the family's expense.[22]

From a personal view, I do not concur with Dr. A's conclusions which would permit physicians to unilaterally end the patient's life. I can understand his argument concerning physicians' integrity, as pointed out earlier by Brody, but I do not read of any final decision in the critical intervention policy. In fact, the policy is vague and unclear. It states that in cases of continued disagreement, the patients have the right to get their own physicians involved and that transfers may be made to another hospital. It does not conclude definitively that attending physicians have the final word in case the patient is refused by other hospitals.[23]

There is another aspect in regard to the critical intervention policy which directly

leads to a family/physician collision. As pointed out in our Introduction and at the beginning of Chapter I, most critical intervention policies deal primarily and sometimes only with doctor/patient communication. Families are hardly mentioned. In real life, most critical interventions that I have witnessed involve patients who are unable to respond and are considered incompetent. At this point, family members usually become involved. Second, all of the policies that I have read do not deal with competent patients who insist on full treatment. For some reasons, which are unclear to me, we read of the ethical dilemmas of patients who refuse treatment, never of the critically ill patient who might insist on full treatment. We read in our own policy, "Although patients must be apprised of the therapeutic plan, they need not be informed of all measures that are to be withheld on the grounds of futility."[24]

Does this mean that a patient who insists on resuscitation or intubation can be refused his/her request on the grounds of futility? Don't families ever have to be consulted, especially in cases of the incompetent patient?

A similar anachronism can be found in the living will. The assumption is that a living will is for people who do not want to live under life support in the futile situation. But what happens when the will would say that the patient wants to live with life support until God takes his/her life? We then seem to invoke Brody's theory of physician integrity which would nullify the will of the patient. The fact of life is that there are many such people of all faiths, and especially in the Jewish faith, who would opt for life support until God takes their lives.

This brings us to a third concern in regard to the Critical Care Intervention

Policies which do not discuss cultural or religious considerations. The religious/cultural background of physicians and health care workers is likely to influence clinical practice. Further, there are limitations of the medical model in a multi-cultural society. Symptoms may differ substantially among ethnic groups which brings into question the viability of diagnostic terms. Problems can be neither diagnosed nor treated without examining the frame of reference of the patient and the health care provider.[25] The medical model focusses on the disease course rather than the culturally based experience of being ill. Western medicine assumptions, including the perception of patients to be punctual, future-oriented, willing to work on therapeutic goals and accept the Western biomedical approach which we lay out for them, do not always work. Sometimes it is as if we are on two different channels or wavelengths which bypass each other completely.[26]

Finally, although Critical Care Intervention policies involve ethics committees, in cases of family inflexibility and intransigence the policies do not mention methodologies which could alleviate the situation. These include arbitration, mediation, knowledge of conflict resolution and even communication. On paper, ethics committees seem open enough; in practice, they follow Zawacki's funnel model which is a tool for physicians who direct the committees to follow their advice.

Dr. B, the oncologist, showed concern in cases of DNR. He said, "I do not approve of the house staff, who do not know the family, becoming involved in DNR orders. I also do not believe it belongs solely to the family. This is a medical decision. You have to be in a position of authority in such cases. This is why university hospitals are sometimes less efficient than non-teaching hospitals. They leave too many things to

interns and residents." Dr. B then related the following story. "A Hassidic gentleman came in to see me with an abdominal cancer. His wife was hysterical. While seeing me, they shopped for second and third opinions. Having found no satisfaction, they went to see their Hassidic rabbi, a supposed wonder-worker. They came back with a prescription from the rabbi. Wanting to please the family, but against my better judgment, I followed the prescription. A problem arose when one of the drugs burned his skin. He became disillusioned and told me he was going to the Bahamas to experiment in an alternative medical approach. I knew this place to be very unreliable. A few months later, he returned to file a lawsuit against me. It went to court and the patient attempted to sue me on religious grounds for not fulfilling his religious needs. I had tried all this time to be civil, but at this point, all communication broke down. I felt awful. You have to understand, Rabbi, I saw this gentleman every second week for a year and half."

The doctor continued, "People think that there is no satisfaction in oncology. It's not true, there is great satisfaction. There is a positive reinforcement in the communication. We see people at their best, courageous, supportive and loving. These are people facing a life crisis. All pretentions go away. We are now dealing with the naked psyche. Most people don't hear this in their daily contact with other people. The oncologist wonders, *Can I be the same as the person in front of me? People are so brave. How will I react if, God forbid, it happens to me?*"

The oncologist, Dr. B, went above and beyond the call of duty with his patient. One can only perceive his sensitivity as he tried his best for the sake of the patient. We also note how he was attacked in the end for being insensitive to his patient's needs from

a religous perspective.

What do we learn from this story? Without being profound, it's a human story. People simply hear and see what they want to hear and see. This may be especially true if we have a terminal illness. Logic and religious ethics become distorted. The patient and family seem to wear blinkers which narrow their vision. As a rabbi, I often work with such families in times of crisis. These are families that are hurting very deeply. Decisions have to be made quickly. Conflicts may occur within the family. "What should we do?" Their responses are often polarized towards two extremes. Within the framework of *halacha* (Jewish religious law), some families may seek to rationalize their actions, permitting procedures which, in their daily view, would normally not be acceptable. These usually occur in cases of therapeutic abortions which in certain *halachic* circumstances would not be permitted. The abortions are done quietly, confidentially, strictly between doctor, patient, family and sometimes the rabbi. We also witness similar difficult decisions in heart transplants normally forbidden by Jewish law.[27] The law is then stretched and bent, permitting the transplant under "special circumstances". In cases of terminal illness, we have competing values, as mentioned in our first chapter - sanctity of life versus allowing the moribund patient to die without interference of heroic measures. Choices have to be made. Ofttimes, feelings of personal guilt engulf the family's decision. They choose the more stringent approach. The families are often left struggling with these decisions for years after the decision was made.

Our impatient Dr. C explained family involvement in this manner. "Today

families are connected to the Web. They know more than the doctors. You have a responsibility to tell them everything. When I tell patients and families about DNR, it depends on my mood. How happy am I that day? It also depends on the time of day - and it's the same with the family. Truthfully, I have no answers, each family is different, each doctor different. Families should be encouraged to participate, but it takes time. Families have rights in the futile situation. Doctors have no alternative but to go along with the family. You can't play God. But who is going to pay for all this?"

Dr. C had a solution - the two-tiered system. "Further to this system, there should be a special tax for giant corporations such as banks, Bell Telephone, and pharmaceutical companies. Perhaps a 10% tax taken towards Medicare. There should also be a pool of retired doctors who could work in palliative care with families. They would do an excellent job. Finally, let me tell you a story. "A guy comes into my office boasting that he got an MRI done very quickly in the United States. I said, *You're better than me. I can't do it.* [PATIENT:] *Hey, maybe you want to be a partner with me in the MRI business.* [Dr. C:] *Okay, you buy the machine, I run it.* [PATIENT:] *Like hell, I don't trust doctors.*" Dr. C and I both laughed and said together "Smart guy".

Our young lady physician in Geriatrics, Dr. E, continued with her soft approach. "Futility is really not a major problem with me. You have to be patient and explain it clearly. In regard to asking DNR for patients and family, this should be explained to families by the attending physician or residents covering on weekends. It always has to be reviewed and countersigned by the attending physicians. Our DNR policy is not

etched in stone. It can always be reversed. Rabbi, in my mother's case I wrote a DNR. For somebody else's mother there may be no such order. Each family is different. Each case is different. The onus for such decisions should not be entirely with the family. On the other hand, it is primarily the family's decision and there should be meetings with the family."

It is quite possible that my research did not involve enough female physicians. Dr. E. is the only lady physician interviewed. It is possible that there may be a gender difference in response. Perhaps female physicians are more compassionate and verbal and give more time to patients and families. Studies have been made along these lines.[28]

Dr. F, the surgeon, emphatically insisted that families have rights which should be respected. He also expressed difficulty in writing a DNR order. "Doctors are there to preserve life, not to take it away. This whole business of DNR was unheard of years ago. It's all the fault of budget cuts and we are forced to stand by and watch the demise of the patient. Families do have rights." Dr. F then proceeded to tell a story of a physician cancer patient whose family demanded TPN (Total Parenteral Nutrition - an expensive treatment). The attending physician refused, claiming that TPN was inappropriate because studies showed that it could increase the cancer growth rate. The family took out an injunction against the physician who was then forced to administer the TPN."

"Doctors dislike the title *futility*. It's threatening. Palliative care takes the burden off their hands. Social workers don't like the title *futility*. Nothing is *futile*. We just

invent a new treatment approach. It becomes the *palliative care* approach or the *caring* approach, or *making the patient comfortable* approach, but we don't use the word *futility*. The goals of medicine change in these circumstances, but we are burying our heads in the sand. There *is* futility. It's a fact of life, although nobody likes the word. That is why palliative care is not that honest. They don't tell the patient directly that they are dying."

Although one may disagree with Dr. F's strong vitalist approach, he does point to a glaring weakness, the ambivalence we have towards futility. We, in our hospital community, can't seem to come to terms with the word futility. We argue about definitions. When is a case truly futile? Is each case different? There are so many different variables to consider. But, perhaps, Becker[29] is right - we all have innate fears of death.

Coming to terms with the inevitable doesn't necessarily take away our fear of the inevitable. I recall attending a conference eighteen years ago with Dr. Balfour Mount, a pioneer in Canadian palliative care and the founder of the Royal Victoria Hospital Palliative Care Unit. He led a discussion titled, "Telling the Truth to the Patient in Palliative Care". He explained how the truth can be helpful, soothing and important to the family as a whole. A month ago, I was interviewing a nurse for my research. She apologized for coming late to our appointment, explaining that she had just returned from a session of the RVH which was debating how to tell a patient the truth in palliative care. I was astounded. Here we are eighteen years later and still debating and struggling in truth-telling to a palliative care patient who probably has a very good idea of why he or

she is in the Unit. As late as 1995, our clinical ethicist, Dr. Benjamin Freedman, led a week-long conference in medical ethics, titled, "Telling the Truth to the Patient". I recall one of our guest speakers, Robert Buckman, explaining that each case should be handled on its own merits. Not everyone necessarily is ready to hear the whole truth and nothing but the truth. The stumbling block may be Becker's thesis and the fact that hope is diminished. Not all patients can switch gears towards newer goals and ideals. It's not easy. No doubt, the vast majority of physicians believe in telling the truth to the patient at one point or another. Dr. F seems to disagree, although he did admit to me that "some patients can be told the truth when they are leaving the hospital, but only if they insist". Perhaps for Dr. F this is a personal form of abandonment. It was easier for him not to directly face the patient in the hospital. It may also be possible that my experience in general is primarily with physicians of the Jewish faith who are expressing their experience with Jewish families.[30]

Dr. G, the prominent scholarly surgeon, is very close to Dr. F's thinking. "Futile situations happen fairly often with me. I try to dissuade the family from treatment, but you have no alternative. You respond to the needs of the family and operate on the patient. As for DNR, I am uncomfortable. It frightens the family. We manipulate the family. This is not fair or the right thing to do. But physicians are human too. I recall when my family was asked numerous times to make decisions about my brother. We couldn't do it. But what's right for me may not be right for others. In a crunch, you must go with the family." Dr. G has touched upon issues of physician manipulation and that the family was asked numerous times to make a decision which the

physician thought appropriate. This will be discussed more fully in my later chapter on physician/patient/family communication. Suffice to realize at this time that a physician as family member saw the communication as manipulative and that he felt it was not right for his family.

I also find this thread of paternalism in Dr. H's attitude towards his patients. "In cases of futility, if the patient is competent, we go along with the patient. If the patient is incompetent, we can depend on the experience and charisma of the physician. The physician's position is to be able to convince our family towards the right decision. Even if the family is religious, they will probably agree with the physician. If the physician does not know the family well enough, he should not be involved. Further, the patient and family have to be ready to receive the information. Timing is important."

Dr. H, in my opinion, is somewhat unrealistic. Religious families are not easily persuaded. I once heard a family member shout at the Head of the ICU after he pronounced futility, "You are not God. You can state your opinion, but you are not God!" Although most religious families would have been more respectful, their sentiments are similar. Doctors are forced to play God but they are not God.[31]

Dr. I, the oncologist who switched to gynecology, also claims that family have rights. "They must be considered. They are the major caretakers. The problem with DNR is that the doctors have to be honest. How would they feel about a DNR on their own lives or the lives of their loved ones? Physicians also have their own problems in communication. The universal concept of telling everything to everyone is a cop-out. It is not acceptable. We have to consider the type of patient, their mental strengths,

length of illness and if they are ready. The same can be said for the physician's capacities. Another problem is cost. The physician should not look at financial costs, but there is a reality which affects many decisions. It's a disgrace when we send home patients too early. In Obstetrics, we have mechanisms for an early discharge. As for family/doctor confrontation, naturally we go with the family."

Dr. I has brought the physician's communicative abilities to the fore. No doubt, this is a major problem. Unfortunately, many physicians play "hit and run" when they first tell the patient the bad news and then run.[32]

Dr. J in Pulmonary Medicine argues that in cases of futility "sometimes you have to get other doctors involved to convince the family. We have to be honest. Although I go along with the family, there is a difference in the ICU. Families cannot tell the doctors what to do in the ICU. The pressures are different. There are bed shortages and the patients are in a different position than when I see them and communicate with them. Personally, I go along with the families feeding the PVS patient even if I don't agree. Our DNR policy has gone too far in its discussion of these issues. Each patient is to be treated differently. Physicians who do not know the patient are making important decisions and should not be talking to the patient about DNR. The major problem is that we have no time for patients so DNR protocols are set up to facilitate doctor/patient relationships which are time-consuming."

Dr. J, in my opinion, is somewhat simplistic. The DNR concept can help the patients, families and physicians think about treatment plans. It may also clarify a muddled family situation when fully discussed. The major problem is that in certain

situations, patients and families may change their minds about DNR. This can be expected and is a normal response.

In a study attempting to describe the difficult decisions of seriously ill patients near the end of their lives, Elizabeth F. Hiltunen et al write,

> One of the most frequent challenges in translating patient autonomy into practice is that seriously ill patients and their families may face serious decisional conflicts in making end-of-life treatment decisions. Janis and Mann describe decisional conflict as the *simultaneous opposing tendencies within the individual to accept and reject a given course of action*. Prominent symptoms are hesitation, vacillation, feelings of uncertainty and signs of acute emotional stress whenever the decision comes within the focus of attention. In a national survey, critical care nurses have reported the incidence of decisional conflict in critical care cases to be as high as 24%.[33]

The results of this study which emphasized the prevalence of ambivalence and vacillation in making decisions at end of life show that DNR orders are only the beginning of a process which allows and encourages open communication between family and physician. The same rationale may be used for living will decisions. Because vacillation and indecision are only normal at end of life, the living will is only the beginning of the process which should be part of the family's discussion about the end of life. Thus, meetings between physicians, patients and families are often time consuming and most uncomfortable. Our hospital policy on DNR is a perfect example of the difficulties of implementing such a policy. For when decisions are made unilaterally by physicians and even explained to the family, the families may feel that the players in this process have just given up and that very little in general will be done for the patient. The Jewish family, with its emphasis on the sanctity of life, on the other hand, may want to protect loved ones. It becomes quite complicated.

In the summer of 1998, I went to visit a patient at the Royal Victoria Hospital. After introducing myself to the nurse in charge, she whispered, "You know, rabbi, he is a DNR candidate." I whispered in return, "How do you make such a decision?" She replied, "It's always the family. We seldom talk to the patient." I wondered about the friend whom I was visiting. He was lucid, but knowing his wife, I knew that she would be protective. It seems as if it is not only our hospital which protects its patients.

Dr. K, the Palliative Care specialist, and Dr. L, the researcher, both agreed that the family should have the last say in cases of conflict. Dr. L asked, "But what do we do if the patient has been demented for five years or if the patient is jaundiced and it would be inappropriate to initiate an operation? In a teaching hospital it may be okay. We could learn. But it's wrong. Another problem is our use of the non-directive approach in all communication. The doctor and clinical ethicist have abdicated their leadership roles." This last observation from Dr. L. is a controversial issue and will be discussed in our final chapter.

Dr. M, the Chief of Family Medicine, advises "that in cases of conflict between physician and family, it is the right of the physician to say, *I can't support your approach. Please find another doctor.*" I believe that in Family Medicine this is quite appropriate, but when the patient is on life-support systems it is very difficult. In the Intensive Care Units, families and patients must work with the ICU team. Although our protocol suggests the right of a patient to call his own doctor, this is very difficult in an ICU situation since it is a very specialized unit.

Dr. N, the former Chief of the ICU, was also a general surgeon.[34] He tried to

arrange conversations before his operation so that families knew clearly the goals and options during and after the operation. "In case we find X, we will do Y. We try to explain the options to the families in all cases. For instance, if the heart stops, we often have to tell the family in advance that there will be no resuscitation. It is not a question of asking the family or patients *Do you want resuscitation?* We know what we have to do and our options. Autonomy does not mean a patient or family can demand a treatment. With every right there is an obligation to others. The doctor has a competing right of a physician's integrity. So what do we do? We negotiate treatment goals. We then see what's available, appropriate and reasonable."

The lack of resources was a major contention for our ICU doctor. "Justice is a right to a process. Distributive justice tells us society as a whole should have access to this same process. When resources are low, we make choices. One chance in ten is okay. There are times when we have to wean patients off the respirator. We believe that decisions to remove a ventilator is the same as not placing the ventilator on in the first place, so if it is inappropriate, then you can turn it off. Eighty-five percent of the deaths in the ICUs all over the world involve withholding or withdrawal of ventilators. These statistics come from our last World Critical Care meeting which I attended. What do we do if we know the outcome is not good? To prolong the battle is not worth it. Rabbi, you know what resuscitation is like. If dying patients and families really know what resuscitation was really like, they would not make that choice. The greatest tragedy in the ICU is when families badger me to continue treatment. Then we notice how visits become less often. At first they were at the bedside every day and then it's once a week.

It doesn't take long until I hear, *Doctor, about how long do you give her?* I am tempted to say to the family, *You did this to your mother. You made her suffer so.* But I shut up."

As one can well imagine, as chaplain of the Jewish faith, I ran a fairly constant battle with Dr. N on a few issues. I fully understood his position when families agreed to remove the respirator. However, when families who are the surrogate decision-makers disagreed, removing the respirator should not have been permitted on the grounds of futility. Before I discuss my points of contention, allow me to give a little background.

Dr. N was a very imposing figure. He was extremely heavy-set. When he met with the family, he dominated the scene. He elicited a powerful sense of presence which intimidated his audience, sometimes even in the presence of other doctors and nurses. When meeting with the family in the futile situation, he first asked the family how they saw the prognosis. Then he explained and elaborated on the futility issue and what he would like to do. Then he asked for their opinions. In the vast majority of cases, there was hardly any two-way conversation. He was the Head of the ICU "and who are we to disagree".

Dr. N ran an extremely efficient ICU. He developed a teaching program which attracted nurses and residents from hospitals and universities other than McGill. Dr. N kept a high profile. He dominated the ICU. He ran a tight ship. His staff loved him and protected him from all outside incursion. He could be warm, friendly and loving, but was extremely sensitive to any type of criticism. Generally, other staff surgeons felt

uncomfortable in his presence and hardly showed up in the ICU unless he called them. The ICU was his baileywick. Nobody could interfere.

Dr. N had been involved with a few legal disputes. He was a gentleman of principles and would fight for what he believed in. Recently, he was the main player in the Henry Krausz case which has drawn world-wide coverage. He was also Co-Chairman of the Hospital Ethics Committee. No doubt he was well-read in medical ethics.

From my personal vantage I saw Dr. N as an excellent physician and surgeon who was caring and knew of each case in his 15-bed ICU. He was the key to its success. He fought like hell for his patients. I recommended many people to his care. Dr. N knew this but still got angry as hell when I disagreed with him. But we respected each other. I tried not to be intimidated in his presence. His approach was powerful. Secondly, the medical decision in futility is a powerful weapon by itself. It can be devastating, especially when families are close and loving. How does one dispute the doctor's opinion? How do you communicate when the professional tells you there is nothing more that can be done? The only way I know of is to be sensitive to a hurting family, always giving them an opportunity to digest the information and a window to express themselves. The family must not be expected to accept the information immediately. We might ask, *Perhaps you want a second opinion? or perhaps you want to think it over and speak to us in the morning?* Even if we agree with Schneiderman, Jecker and Brody, futility should not be used as a trump card. I now offer my points of contention.

1. There should be no difference between the will of the patient and the will of the family on the basis of futility. In other words, if the patient is competent and asks not to be removed from the respirator, the family should also have the same rights for the incompetent patient. And if we do not heed the family in cases of futility, we should not heed the patient as well.

2. Dr. N believed, as others, that there is no difference between initiating or removing a respirator. The theory is that each breath a patient takes through the respirator partly initiates the breathing process. In my view and in the view of all the families I have interviewed, this is splitting hairs. Removing the respirator is simply mercy killing. The same analogy can be used for the PVS patient who is removed from the feeding tube. We could say that each drop of liquid fluid, by itself, initiates the feeding process. On the other hand, we can say that by removing the feeding tubes we are in the process of starving the patient and mercy killing. This is quite different from deciding not to initiate respiratory therapy or give antibiotic treatments when we know the patient will die imminently.

3. Dr. N believed that futility was a license to remove all life-supporting equipment. This is in agreement with Schneiderman, Jecker and others. In fact, they once claimed that families do not have to be told. (They changed their minds. Now families are told.) But we know that there are other ethicists such as R. Veatch, T.A. Raffin, M. Angell, S.N. Wolf and others who disagree. Further, a host of Jewish religious ethicists point to the sanctity of life as the major issue. Dr. N's

ethics seemed to be etched in stone.

4. How far are the ICU's policies from permitting physician-assisted suicide? Even when the patient asks to be taken off the respirator, we slowly turn it off knowing that the patient will die. Are we not on the "slippery slope"? I am reminded of some conversations which occasionally happen, I am sure, to many in Chaplaincy. We visit terminally ill patients who are in pain. "Rabbi, I am tired and in constant pain. Enough is enough. C'mon Rabbi, do something for me. You have access to pills. I can't take it anymore." I am not certain if the patient really means it or not, but if it is true, it is very similar to the futile case in the ICU. The patient is also saying "enough is enough". He/she agrees to remove the respirator to help him/her die.

Dr. N avoided my concerns. He was in a tough position. ICUs are struggling because there is a shortage of beds and a shortage of funds. ICUs all over the world would agree with his approach. There are two sides to the issue. I believe we are on the slippery slope and since we are in a Jewish community hospital, perhaps he could have been less rigid. He believed that I should have changed my views and supported him and his staff.

Assessing the Interviews

From my interviews, I may note the leaning and bias of each of the physicians towards the four major models of how the physicians respond in cases of futility. Before making this assessment, I will briefly review the four models.

The first model stressed physicians' rights to decide on cases of futility, since they are the primary movers in each case. Families have no rights to intervene in medical issues which are not in their domain or their expertise. Giving the family a right to override any medical decision undermines the integrity of the whole profession.

The second model emphasized patient and family rights. This is based on the rule of patient autonomy. Each patient has the inalienable democratic right to decide what is right for him/herself. We cannot impose any of our beliefs, opinions or decisions upon others. In cases of incompetency or when the competent patient leaves the decision to the family, the family takes over this right. The belief is that the patient is part family and the family is part patient. They know the patient best.

The third model gives prominence to the concept of justice and fairness. We endeavour to balance the rights of physicians and patient autonomy with a resolution involving the cost of resources, allocating these resources in the way which would be fair to the users of our medical system. Decisions are not only in the hands of the physician or patients. The medical system involves our whole society and we must be just and fair so that we all may have equal access to health care. For many, this is a realistic approach.

The fourth and final model stresses communication. The belief is that only through communication can a consensus take form. The rights of physicians, patients or society are meaningless if we do not have the means to find agreement. The key to all decision processes is communication. The problem is how to communicate and find this consensus among the players.

At the outset of this discussion, I must make it clear that all four models are not mutually exclusive. The designers of the models are physicians and ethicists. They are the ones involved. They know the different points of view. In my opinion, almost all of the physicians interviewed understood the importance of communication. In moments of differences in opinion, we all try to convince our adversaries. They also recognize the role of administration. There has to be some control in order for the system to work. Almost all realize that patients and families have rights. They would place limits on these rights but in the final analysis most recognized that the patient and the family do have the final say. The physicians have the knowledge and expertise but in the end they could ask themselves, "Whose life is it anyway?".

From the responses, however, I could sense the different lines of reasoning favouring certain approaches to resolve the futility debate. Doctors A, M, and N seem most bent on physicians' rights and duties as the primary factor. Doctor A believed that only the absolute truth was important. Although one may argue that Dr. A was primarily interested in communication, he didn't seem to show concern about the readiness of the patient to accept the news or whether he could use a softer approach. In every case, we are told to tell the absolute truth. I see it as part of a syndrome which places authority

in the physician. The physician is speaking from a position of authority and has decided what is in the patient's best interest, and in each case the patient's best interest is to know the truth. I have doubts regarding this motive. It may be that telling the truth makes the physician more comfortable as he/she will not have to hide the truth. In my experience, it borders on a paternalistic attitude, not being sensitive enough to understand the feelings of a patient who is dying. It would also leave room for abandonment as if to say, "As I am telling you the truth, you must know that your case will be transferred to another doctor who specializes in palliative care and pain control." Most of the other doctors did not take this candid approach. They individualized each case. They were cautious, never leaving the patient without hope. Dr. M had a softer approach, but at the same time let the family know that if they did not approve of his decisions, they were to find another doctor. Dr. N, of the ICU, had absolutely no room in his thoughts for patient autonomy. The hospital belongs to the physician and the physician makes all the decisions.

Doctors B, F, G, J, K and L all seem to favour, in the end, the family. They did so reluctantly. Theoretically, according to the physician-patient contract and the CMA code of ethics, the physician first advises with the patient. In practice, they are firstly and primarily in contact with the family. It is not easy to approach an elderly patient with chronic heart disease to discuss DNR orders or even deliver the bad news. Physicians avoid it whenever possible. For this reason, I believe, many hospitals have questionnaires for patients in admitting asking if they want to be resuscitated and have heroic measures if necessary. It eases the pressure on the physicians on the floor. Their

questions have already been answered.[35]

Analogous to this concept is the philosophical and religious thinking of many of the Jewish faith. They may express belief in *bashert* (fate as decreed by God) but in practice they fight like hell for life. After it is over, and the patients who may have been in their late eighties or nineties die, we often hear from the family, "It was the doctor's fault."

Further, this cautious approach by the above physicians involves all patients who are terminally ill. We never really know how patients will respond to their illness. As Dr. B pointed out, most learn to accept reality and are brave; others want to live in two worlds - denial and reality, some only in denial, while still others become completely paralysed and devastated. Each patient is a world unto themselves. Each must be treated separately. This is what makes it so difficult.

A third group of physicians, including Dr. C, D, I and others, seem to favour the model based on fairness and justice. They pounced on the "system" which did not allow any place for a physician to practice proper medicine. They spoke of delays waiting for tests, financial constraints, poor equipment, unfair pay schedules for the physician, and concern for the patient who receives poor medical care in the end. My questions on doctor-patient communication seemed almost ludicrous to this group of physicians. There was just no time for communication within the present system. Some of the physicians, especially Dr. H, were adamantly opposed to connecting futility with shortages in resources. As mentioned above (p. 163), they wished to distinguish the issues, arguing that decisions on patient futility have nothing in common with distributive

justice. Futility decisions are based on what is in the best interest of the patients, while resource allocation and distributive justice are societal issues. In reality, it doesn't work this way. Each patient is part of our society where justice and fairness are intrinsic values. Dr. N. in his ICU, faced this problem daily. Who gets the ICU bed? He looks at the patient's chances for recovery while calculating costs. How long will this patient in the ICU stay? What will happen if it's futile and someone else needs the bed? Is it just to send an older patient out of the ICU in order to allow a younger man to enter? At what point do we stop treatment or do we spend more of the budget to try a more expensive and newer treatment, and if this treatment has a slightly higher rate of success, do I use it routinely when costs are crippling our department? A similar series of questions may be asked throughout the hospital; in each department, upon each ward, doctors and nurses face higher medical costs. The head nurses ask, "Where do I cut from patient care?" The physician asks, "Perhaps this patient will improve with this more expensive drug. Should we order it?" The administrator asks, "From which department should I make my cuts? Or whose job do I eliminate?" The family asks, "Maybe we should have gone to the States for an MRI. There should be a two-tiered system. We can afford it." Or we hear, "How come there is a two-tiered system? It should not be allowed in our Canadian way of life. It's not fair or just." Theoretically, Dr. H. has a point. Futility decisions should be patient-oriented, each patient on his/her own merit. Sadly, in the real world, we are forced to make life and death decisions based on shortages of resources and how we should allocate these resources.

Communication as the major model was espoused by Drs. H, O, and P and

especially the young lady physician, Dr. E from Geriatrics. In emphasizing the role of communication, these physicians were other-oriented, interested in the feelings and concerns of others - not in expressing their own opinions of who is right or wrong in the debate. The main issue is a form of agreement, difficult as it may be. In the process of seeking this consensus, the players may find a sense of coming to terms. They realize that we care and agonize with them. In the end it is the process which is important, not that we approve any point of view. There is also an art to communicating. Part of this art involves listening to another's opinion. I quote from a memo sent to me by Dr. Fred Bird in a critique of this thesis.

> I suspect that it is important to encourage or require doctors to allow some time to listen to patients and families. I do not know how this can happen, given the constraints of the existing health care system. However, it seems important to make this recommendation for several reasons which I will explain.
>
> a) By listening, the doctors will be better able to know how to communicate. They will be better able to know what is on the minds of the family and patients.
>
> b) By listening, doctors will also provide more time for families and patients to think over the options before them. There is evidence from studies of organizational justice that workers are much more likely to regard decisions as "just" if they have had some opportunity to express their feelings and thoughts about them... even when the final decisions are in no way different.
>
> c) By listening, doctors are allowing patients and families to be involved in the process. Families often feel very helpless. That is partly why they ask doctors to try every means. Because they feel helpless, they try to get the doctor to compensate for and address their own sense of helplessness by being extra-ordinarily powerful. However, as family members are allowed to talk, they feel they are doing something. They are also in a more practical position to sort out their feelings.

From my experience, Bird is right. The problem is how to get doctors to listen when they are in such a dominant position and harassed for time. Their very *raison*

d'être places them as the powerful healer while patients come to them as helpless consumers. From the beginning, we are all brought up to believe that doctor knows best. Television programs reinforce this image. Physicians assume that with their superior knowledge and experience, they can judge what the patients need. There may be options, but the physician can decide the best option. It is almost as if patients have given up their fundamental rights to know and to decide.

Further to this attitude is the physician's place in a hospital system which advocates the administrative model approach. A patient's stay must be as brief as possible. We treat the illness, disease, and the patient is sent home as quickly as possible. As Dr. C pointed out, "Who has time to communicate? And when I communicate, do they understand?" "When the patient is deathly ill, he often doesn't want to communicate." "Who has time for informed consent? We would have to explain the pros and cons of every procedure and test."

An Analysis of Physicians' Responses

I now turn from assessing the physicians' interviews to analyzing them in terms of the hypothesis I have suggested. I will also offer a newer set of hypotheses in regard to the results of our research.

In Chapter II I examined and elucidated upon three major historical changes in the medical profession. Until 1971, doctors were in the primary position. They were in control of the hospital and the health care system. From 1971, with the advent of

medicare, much of the control was taken away from the physicians and given to the patients.[36] Physicians, *en masse*, reluctantly joined medicare. In effect, they became government employees. Their influence on the Canadian medical scene waned. Patients became more in control of their medical needs. In the 1980s, as costs began to soar, the Quebec government implemented its first Plan de Redressement - which cut our hospital budget by two million dollars. From the 1980s until the present, government has continually chipped away at the medical system and began playing the major role in health care. Today, in our hospital as in others, government indirectly controls hospital policy. The physicians in each department receive instructions from the DPS (Department of Professional Services) offices. The DPS office follows instructions from administration who in turn get their instructions from the government. In the graph below, we can understand what has happened to the physicians within the last forty years.

The Three Major Medical Eras of our Time[37]

Table 1. Three Major Medical Eras

	ERA I (up to 1970)	**ERA II** (1970-1985)	**ERA III** (1985-2000)
1	Physician	Patient	Administration
2	Hospital Services	Physician	Physician
3	Nursing	Nursing	Patient
4	Patient	Hospital Services	Nursing
5	Auxiliary Services	Auxiliary Services	Hospital Services
6	Administration	Administration	Auxiliary Services

If we examine the above model, we will note that in Era I, the physicians were in the spotlight. They were king. Number two in service to the physicians was Hospital Services, which included the labs and technical equipment which helped in diagnosis and treatment. Number three was Nursing. The physician, most often, was fearful of nursing. The nurse was his right hand. Number four was the Patient who gave him his bread and butter. Number five were the Auxiliary Services such as Physio, Occupational Therapy, Pastoral Services and number six was Adminstration who were always "a pain" when you had to deal with them. In Era II as the physicians began losing their clout, the patients became the primary focus. Physicians became number two to the patient, reluctantly giving up their primary position. Nursing remained number three, hospital services number four, auxiliary services, number five and administration, number six. Administration was still taken for granted. The biggest change came in Era III. Suddenly, administration became the centre point and began running the show. It was as if the government was telling us, "Welcome to the real world. Now we will tell you how to run a hospital. We decide on salaries. We decide on how many resident physicians you will have. We decide on how to staff nursing. In fact, we will buy out contracts, close positions, and decide on equipment and technological changes. We will tell you that you have to cut back on all services including labs and auxiliary services. We will also tell the patient how long he/she is to stay in the hospital." Thus, an embattled physician feeling abused by the system now remains reluctantly and bitterly number two. The patient unhappily becomes number three. The exhausted nurse number four, the disgruntled technician and x-ray and lab employee, number five, while

physio and occupational and social services and other rehab units become number six. Ironically, the Auxiliary Servies are probably the most needed services at this time.

From my interviews, I could sense the historical framework the physician emphasized. If the physician was professionally-centred, arguing in a sense for the "good old days", very protective of his/her rights and seeing families as outsiders and interfering in their domain, I could hypothesize that he/she was from Era I. If physicians were understanding of the patient and family autonomy, I might hypothesize that they were patient-centred and were primarily schooled in Era II. If, however, the physician was only concerned with the present medical model, which says, in effect, "Never mind the patient or physician rights. Just get the patient out as soon as possible", I could hypothesize that the physician was primarily government and administrative centered.

Turning to my interviews, I looked to the older physicians and surgeons who perhaps remembered best these changes and especially the days when physicians were the primary decision-makers in the hospital. They seemed to respond in a somewhat nostalgic way, expressing complaints and anger at the changes in the system. I noted this especially with Doctors C and D when they saw their income withering and the golden era of the physician fading away. The pot of gold at the end of the rainbow had dissipated. They had even lost their respect, their primary role in the hospital. This is not to say that they did not show concern for the patient. They were genuinely concerned. Futility and communication were important issues. They wished there was more time to communicate. Doctors F and G, both surgeons, also spoke of changes in the system. It was now impossible for physicians to have the time to develop the

traditional doctor-patient relationships. Dr. H still referred to the charisma of the physician as a tool in communication. Dr. N was most emphatic about the integrity of the physician's profession and how it had to be first and upheld in order for medicine, as we know it, to survive. Administrators know nothing of medicine. It became a personal matter to Dr. N. "They never supported me in any of my court cases." Obviously, he didn't begin to appreciate administration who had to answer to the public. He felt scape-goated.

The above assessment is not to say that physicians did not show concern for the patients. They are professionals and their patients are their primary concern. They are, in my opinion, excellent physicians who have helped thousands of patients. Dr. N of the ICU, who always minimized patient autonomy, had a bed in his office. Many nights he did not leave the hospital, always concerned for a patient. I did notice throughout the interviews that the physicians harboured a complete disrespect for administration and government interference. It was as if a battleline was drawn, although they knew that they lost the battle. The practice of medicine just wasn't the same anymore. For some, the pleasure of medical practice had disappeared. They were now going through the motions. Perhaps it was a form of burnout.

The second group of physicians, mostly in their 40s and 50s, focused primarily on patient care. These included, in my opinion, the vast majority of our physicians. Again, I emphasize this does not mean that they agree with government policy. They do not. Perhaps it's their age. They have the capacity to accept and adjust to change, working extremely hard doing a good job in tough times. I recall especially Dr. B from

oncology who marvels at his cancer patients and their courage. Dr. E, the communicator, whose major interest is to find consensus with patients and families. Dr. I, who tries to give as much time as possible to the patient and family and Drs. J and K who recognized the psychosocial factors in patient care. Dr. L, the researcher, had the highest regard for doctors who genuinely care and Dr. M who seemed to pull our attention towards the societal fear of death. And above all, in my estimation, is the sensitivity they showed towards patients and families especially as they had to break the bad news. It was as if it was the most difficult part of their work. I recall how many of them said, "Rabbi, you can't take away hope. Without hope you leave them with nothing." "Break it to them gently. You have to be certain they are ready." "Be cautious. Speak to the family first. Keep it comfortable." Physicians spoke, in my view, from experience. I would tend to agree with them.

The third set of physicians represent the administrative era. This is most notable in Emergency. Prior to the opening of our new emergency area, the Jewish General was notoriously regarded as having one of the poorer emergency areas in the city. The corridors were often filled with patients and nursing stations were in different areas. It was frightening. Government inspectors were concerned. Before building a state-of-the-art emergency area in 1996, an Emergency Room Steering Committee which included doctors and nursing was formed to decide how to arrange the space in order to handle the patients. In fact, in the spring of 1998, administration sponsored the official new opening of the emergency and honoured this committee for their special work, especially how emergency was now set up to release all new patients within 48 hours. The rules

are strictly upheld. No patient is allowed to stay in emergency over 48 hours. The doctors tell me, "Statistically, we are the only emergency in the city which is close to 100% in following the regulations." There is a pride attached to these efforts which is disturbing. It smacks of impersonal medicine. It is as if the 48 hours is more important than the welfare of the patient. Indeed, the department tries to keep statistics on the patients. I am told that despite the quick patient release, very few come back to be treated. I have my doubts. It is not what I hear on the floor as I visit patients and speak to the families. State-of-the-art equipment does not make an emergency department humane.[38]

The physicians in Emergency are young, in their 20s and 30s. Very few older physicians are attracted by Emergency medicine. It's a very high stress area. Patients are older, tests have to be done constantly. Families complain. The doctors are tough. Patients are released in the middle of the night. The physician gatekeepers are also young and tough. One of the finest and highly respected physicians complained, "Rabbi, Emergency is in control of the whole hospital. If you make them angry, they call a surge. It's a constant threat. They've taken it out of our hands." The doctor exaggerates, but it's his perception.

On the floors, patients are released as soon as possible. When I feel it is not warranted, I tell patients, "Don't tell the resident you are feeling better. It signals an effort to have you released. Tell them you are weak and you have nobody to take care of you at home. Perhaps it will help." I use the term "perhaps" because they make every effort to get the patient out of hospital -usually with great success. Within hours,

the bed is filled again.

We often muse, physicians, staff and myself, about the government's purpose with all this quick fix medical model approach. It costs the government the same. Beds are full to capacity. While we relieve emergency, the hospital does not save any money. Our only conclusion is that government is interested in numbers. Treat as many patients as possible. In the meantime, they cut back payments to the hospital claiming that shorter stays save money. It's very political.

Returning to my thesis, I have suggested that the age of the physicians and the era in which they primarily trained will affect their response towards futility. The older physicians are more profession-oriented, concerned with their role and esteem. The middle-aged physicians from ages 40 to 60 are not so concerned with their own personal dignity. They seem to be more patient-oriented. We may notice this in their manner of dress. An older physician told me, "In my days, when we visited patients, we were dressed with ties and a white coat. We were immaculate and proud as we walked down the corridors. Today, physicians are dressed like farmers in jeans, open shirts, and unshaven. It's embarrassing towards our profession." I replied, "Doc, don't feel bad. It's the same for rabbis. In older days, we dressed in dark suits, white shirts and ties, summer and winter. Today, some of our graduates wear jeans, sports shirts, are unshaven and I have even seen one who had the *chutzpah* of wearing a headband while carrying a guitar." The principle is the same. It's a reflection of our times. From the original proud and sometimes lecture-giving ambassadors of our professions, we have now become more concerned with our patients and congregants. We want to serve our

patients, clients and congregants and attract them towards our professions and synagogues. In the hospital, we accomplish this by being informal and making the patient as comfortable as possible.

The third group of younger physicians are hospital and administrative-oriented. It's as if they are emulating administration. "Welcome to the real world where we have to control costs. We abide by the rules. Patients don't tell us anymore what we have to do." As I mentioned above and showed in my models, the change within the last ten years is almost a complete reversal of the past. Whereas physicians and patients were once number one, it is now administration. Administrators are finance-oriented. The hospital is a business. They know little about medicine or what is happening on the floor. They look at medicine in dollars and cents. Perhaps the practice of medicine will never be the same.

There are other considerations I explore in my research. Are the different responses from the physicians towards futility connected to their personal ability to communicate well? Do those physicians who have the capacity and desire to communicate accept the role of family as central to solving the futility issue? From my responses, I only noted this capacity from Doctors B and E who seem most concerned about communication. Doctors G, I and K also emphasized its importance while being pressed for time. The others seemed to view communication as a vehicle for communicating the bad news to patients and family. In other words, I saw communication emphasized on three planes. On a first level, communication was telling the patient and family the news. This had to do with the communication and truth on a

continuum. How much do we tell the patient? How much to the family? When is the patient ready to hear the truth? And can we bend the truth? There communication ends. On the second level, the physician recognized that communication goes beyond advising patient and family. They could speak of guilt, anger, depression, hostility and abandonment. On the highest and third level, as I approached conflict and futility, I sensed that these physicians called communication a process over time and that one had to make the time to proceed over the various stages until there was a consensus between patient, family and physician.

A word of caution. When we measure communication and its effectiveness, we know we are involved with competing values, autonomy on behalf of the patient and family, and beneficence on behalf of the physician. Hopefully, they don't collide. But in many situations, we are forced to resort to the concept of phronesis, as mentioned above, which is practical wisdom. We don't live in a world of ideas nor in a world where morals can be standardized. Dealing with conflicts can be very personal, private, religious, and cultural. I see this at the hospital. I interviewed Jewish physicians and families who stem from a specific religion and culture. When physicians face the families of terminal patients, the families may resort to older traditional beliefs. It becomes a personal way out, even if unexpressed as such. The patient, who was never formally religious, can suddenly revert to older religious and cultural beliefs during these difficult times. It can be comforting to be part of a cultural identity. It can relieve tension and anxiety in a troubled family. I also note this phenomenon when doctors and families discuss autopsies which are forbidden in most cases by the Jewish faith. The

conversation can be serious, educational, and enlightening on behalf of the doctor. But the Jewish family, in almost every case, refuses to be convinced. Transplants, although recognized as a *mitzvah* by many authorities, are frowned upon in most instances. I hear, "Doc, we appreciate your argument and your interest, but mother has gone through so much. We don't want to mutilate her body further." Or, "Mother was a Holocaust survivor. We want to leave her be." Or, "Mother was traditional. She would not have liked this idea. I realize that we are not formally religious, but that was never done in our family." And although it is not fair to equate attitudes towards autopsies and transplants to futile situations on the floor which involve pain and prolonging life or death, families in critical situations will sometimes return to their roots. Because of these additional variables of religion and culture, we must be cautious in our measurements and hypotheses of how well physicians communicate with Jewish families in these situations.

I may also hypothesize that physicians from intensive care, geriatrics and palliative care are better communicators than physicians from other hospital departments since they are in constant touch with terminally ill patients and families. Generally, physicians in the ICU are noted to be excellent communicators while the physicians from other areas did not seem to dwell on communication as a method or process. In the futile situation, communication was perceived more as convincing the families that the doctor was right. It was not viewed as communication between two parties over a period of time. It was not a matter of listening or working with patients and families. It was scheduled as a one-way conversation and if it did not work, then the families' opinion

would usually prevail.

Once again, we must be cautious. Firstly, I have not had enough interviews within each department. A single interview does not make a case. Second, there are good communicators in every department. Some physicians give more time to patients, others with full offices rush the patient and still others are just known as good or poor communicators. I am not trying to correlate communication with the physician's expertise in the field. We have excellent physicians and surgeons, some who take time off to continue their education and yet are poor communicators. On the other hand, we have physicians who are excellent communicators, but just average in their medical expertise. Perhaps this is no different than in any profession - except that in medicine the ability to communicate is essential to the patient and family's well-being.

I offer one more hypothesis from my research. I had always been under the impression that the more physicians were involved with ethics, the better their understanding of communication as an ethical process. Autonomy and physician beneficence were not meant to be exclusive points of view. People with knowledge and respect for ethics could work within both positions. There could be a meeting of minds on the various methods and models in arbitration and communication. What I have found is that in hospital situations which deal with life and death questions, it is the process which is the key. Everyone comes out a "loser" and "winner" at the same time. We may lose a patient but we know we cared and did our best. The most uncomfortable part, in my experience, is that most ethics committees, including ours, tend to be hospital-oriented in their decisions, protective of administration and physicians. There

is a sociological phenomenon proven in most institutions which says, "We are a team. We have to protect one another. We have enough problems from the government and community. If we won't protect ourselves, who will?" This approach creates what Zawacki called the "funnel" attitude in which the HEC's (hospital ethics committees) are used as funnels to corroborate hospital, physician and nursing policies. In 1981, when our HEC was formed, the terms of reference included recognizing patient autonomy and the right to an impartial hearing. The HEC was the means for physicians, patients and family to ask for an ethics consult to a neutral and fair-minded body. The HEC should, in the least, be accessible to the public for this type of hearing. They could also monitor patient care with the purpose of being vigilant and representative of patients and families. This is inherent in its title. Unfortunately, this has not been the case in our hospital where physicians control the ethics committee. I repeatedly hear that only physicians can make hospital decisions. Patients and families have no rights in cases of futility. We can listen to them but they have no meaningful rights. One of the co-chairs from the committee constantly reminded me, "with every right comes an obligation. The patient and family cannot obligate me to do something which I feel is wrong." The second co-chair was not as sharp or brusque. He was soft-spoken and communicated well. He carried, however, a very similar belief and was very protective of his partner. In ethics consults, the medical profession and hospital invariably are always right.

I add one more word of caution. I do not mean to negatively judge the HEC. It is a problem. I am part of the system. It is a fact of life in all HECs that I know of. Thus, from my research, I do not see any correlation between ethics and good

communication as a two-way conversation where beliefs and meanings are shared by the actors involved and which allows communication to develop over time.[39] I noted this in Chapter II when I discussed the teaching of ethics to students and residents. One of the major problems in hospitals and universities is the distrust between the physician and the philosopher ethicist.

There is one final observation. I might hypothesize that the physicians and members of the HEC would be knowledgeable in the literature on medical ethics. This is not so. I do note that they do use a liberal common-sense approach which leads to interesting internal discussion. However, in the framework of this committee, the physicians have the final word.

Conclusion

From my physicians' interviews I have learned that good communication is an invaluable part of the art of medicine. Perhaps nowhere is it more visible than in a hospital setting when physicians must advise patients and families of a bad news diagnosis. After hearing and digesting the news, patients and family will often read into the doctor's words. They will count, examine, dissect, and interpret each word the physician told them. "Perhaps it's not so bad. Maybe the doctor exaggerated. Maybe I didn't understand him fully." Indeed, these are delicate moments involving the hopes and dreams of patients, the ability of a physician to show that he cares and the establishment of a newer family constellation which will have to seek the strength to cope

with their loss and continue in the future.

There are three major obstacles to good communication. First, physicians troubled by failure in treatment can be uncomfortable discussing death with the families and especially with the patients. I perceived their need to be the powerful healer, being able to master the situation. The result could lead to the avoidance of any frank discussion about end of life issues and the beginning of a process of patient abandonment. Further, there is a tendency within physician/patient and family communication to try and convince each other of the best solution. In difficult situations we may see the use of a trump card to finalize the conversation. We forget that most such situations can be resolved if we give it time. Second, there is a tendency to make decisions on quality of life which may not be appropriate. This is especially noted in the decision process involving the aged, chronically ill, and the severely ill when the physician says, "There's really no reason to continue. Even if he gets better, there is no hope for any quality of life." This is a value judgement which cuts off communication. Patients and families may think differently about quality of life. An open discussion regarding family values may be appropriate instead of offering personal opinions on someone else's quality of life. Associated with this attitude towards the elderly, demented, chronically or severely ill patient is the belief that time is precious and it's a waste of time to devote any lengthy conversation to those who are in an incurable situation. This attitude probably stems from the culture of the medical model which stresses speedy service, early discharges and emphasis on home care. The consequences, again, may signal avoiding any lengthy discussion with patients and families. Further, harrassed physicians are overworked,

fatigued and stressed. They often don't feel motivated to give extra time to the patient and family. The mood of the doctor on any specific day may be that he is exhausted, curt and often impolite. Third, the physician may be anxious about his/her own mortality and will avoid communicating on life and death issues. Sometimes, I have noted, physicians will avoid the truth in order to end the conversation. It was a little surprising to me that in my interviews none of the physicians discussed any concerns about their own mortality and how it may have affected discussion with the patient and family. I did get the message from Dr. F. who would only tell the full truth to the patient as he/she was leaving for home. I also learned this from family interviews which claimed that physicians communicated poorly, avoiding the issue and abandoning the family. This may also be attributed to having failed the patient and losing the battle to save a life. In any event, the bottom line is that many physicians do not have the skill to communicate, the ability to listen, to know how and when to intervene, and to provide a sense of caring, even if they tell the family, "we can't do anything more for the patient". In my experience, this is what the family wants to know. "The doctor cared, gave his time, and explained the situation so that we could understand."

We may ask, "How do we make the connection to the family? How do we show we care in this most difficult situation?" In answer, there may be a few steps physicians can take which would demonstrate care and set up an atmosphere which would encourage good communication. For instance, the physician may ask about the family and assess the family's situation. How is the family at risk now that the patient is in a medically futile situation? Who is carrying the major burden of the family? Does the family have

access to the available resources? Was the illness a stigma to the family? Is punishment for sin part of the family's thinking? Has the physician enlisted members of the family in the treatment process? In the end, I hope to demonstrate that good communication is the key. Physicians and family must be comfortable in knowing that a meaningful relationship exists and that the lines of communication are open.

Notes

1. Susan B. Rubin, When Doctors Say No - The Battleground of Medical Futility, pp. 47-55.

2. M. Angell, "The Case of Helga Wanglie", *New England Journal of Medicine* 325 (1991): 511-512.

3. Howard Brody, "The Power to Determine Futility", The Healing Power (New Haven: Yale University Press, 1992), 179.

4. B. Lo, Futile Interventions in Resolving Ethical Dilemmas: A Guide For Clinicians (Baltimore, Maryland: Williams and Wilkins, 1995), 73-81.

5. Norton Spritz, "Physicians and Medical Futility: Experience in the Setting of General Medical Care", Medical Futility, p. 38.

6. Pp. 56-58.

7. Laurence Schneiderman and Nancy Jecker, "Futility in Practice", *Archives of Internal Medicine* 153 (1993): 437-441.

8. Laurence Schneiderman, Nancy Jecker and A. Jonsen, "Medical Futility: Its Meaning and Ethical Implications", *Journal of the Annals of Internal Medicine* 112 (1990): 949-954.

9. "Consensus Report on the Ethics of Foregoing Life-Sustaining Treatments in the Critically Ill", *Critical Care Medicine* 18 (1990): 1435-1439. This approach is identical to the guidelines offered by the Hastings Center. See p. 32.

10. R. D. Truog, A. S. Brett and J. Frader, "The Problem with Futility", *New England Journal of Medicine* 326 (1992): 1560-1564.

11. In later writings, Truog admits to have been mistaken: "Even physiological futility is not value-free". See R. Truog, "Progress in the Futility Debate", in *Journal of Clinical Ethics* (Summer 1995): 128-132.

12. Laurence Schneiderman and Nancy Jecker, Wrong Medicine, 65-68.

13. Howard Brody, "Medical Futility: A Useful Concept?", Medical Futility, eds. Marjorie B. Zuckor and Howard D. Zuckor (New York:Cambridge University Press, 1997), 8.

14. Bruce E. Zawacki, "The Futility Debate and the Management of Gordonian Knots", *Journal of Clinical Ethics* (Summer 1995): 121.

15. *Ibid.*, 122.

16. *Ibid.*, 118-122.

17. Phillipe Ariès, "The Hour of our Death", translated by Helen Weaver (New York: Knopf Publishing, 1981).

18. Daniel Callahan, "Ethics and the Medical Ambivalence Towards Death", *Humane Medicine* 10, no. 3 (July 1994): 177-183.

19. *Ibid.*, 178.

20. I have seen families who send parents, husbands, wives or children to physicians in the United States who have promised them new and different treatments. Families spend hundreds of thousands of dollars mortgaging homes, completely disrupting and destroying their home life, all to no avail.

21. Also see Dr. Benjamin Freedman's book, Duty and Healing Foundations of a Jewish Bioethic (New York: Routledge, 1999).

    I argued with Dr. Freedman. Many doctors also have a strong sense of duty attached to their profession. In the futile situation, it is possible that both duties collide. But Dr. Freedman's concept of duty versus rights is a landmark observation. Doctors emphasize "rights" while families always emphasize "duties".

22. Policy and Procedures Concerning Resuscitation and Other Critical Interventions, Ethics Committee of the SMBD- Jewish General Hospital (May 28, 1999): 4-8. The policy may be found in Appendix A.

23. Our hospital Critical Intervention Policy is presently (February 2000) being updated in the Ethics Committee. It may be considered ambiguous, unclear and does not set any clear standards. I am only presenting a personal understanding of the policy as I read it.

24. Policy and Procedures Concerning Resuscitation and Other Critical Interventions, Ethics Committee of the SMBD- Jewish General Hospital (May 28, 1999): 5. The policy may be found in Appendix A.

25. Lea Baider, Penina Ever-Hadani and Atara Kaplan Denure, "The Impact of Culture on Perceptions of Patient-Physician Satisfaction", *Israel Journal of Medical Science* 31 (1995): 179-185.

26. My approach to a cultural model of illness was taken from Kerry Bowman, clinical ethicist at Mount Sinai (Toronto), at a lecture he gave at a discussion of health care strategies and cultural diversities in March 2000 in Toronto, Ontario.

27. Transplants are generally permitted by most rabbinical authorities. Heart transplants, however, are forbidden because by making the transplant, we are killing the donor. See Rosner, Fred, "Modern Medicine and Jewish Ethics" (Yeshiva University Press, 1986), 255-277.

28. Judith A. Hall, Julie T. Irish, Debra L. Roter, M. Ehrlich and Lucy M. Miller, "Gender in Medical Encounters: An Analysis of Physician and Patient Communication in a Primary Care Setting", *Health Psychology* 13, no. 5 (Sept. 1994).

29. E. Becker, Denial of Death (New York Free Press, 1973), Chapters 1 and 2.

30. Nicholas A. Christakis and David A. Roch. "Physician Characteristics Associated with Decisions to Withdraw Life Support", *American Journal of Public Health* 85, no. 3 (March 1995): 367-371.

31. The expression that "doctors are forced to play God but they are not God" is a popular aphorism because physicians are forced into this difficult position. By the same token, however, we can say that "families are forced to play God but they are not God".

32. Jay Katz, "The Silent World of Doctor and Patient", (New York: The Free Press, 1986), 207-230.

33. Elizabeth Hiltunen, Cynthia Medich, Susan Chase, Lynn Peterson, and Lachnen Forrow. "Family Decision-Making for End-of-Life Treatment: The Support Nurse Narratives", *Journal of Clinical Ethics* (Summer 1999): 126-134.

34. Dr. N died in May 1999. We miss him.

35. In my opinion, this approach can be quite dangerous. Physicians and family can look to a signed consent form from a patient who knows little about his/her situation or the changes which may occur during hospitalization. The JGH does not have this form. It may also be frightening to a patient upon entering the hospital.

36. The Quebec government had begun paying hospital bills in 1960. In 1971 Global Budgeting came into effect. Each hospital received a global budget which was to cover expenses. Changes were subtle. The government generally acquiesced to hospital needs if they could be proven. It was only in the 1980s that the government reared its head and bared its teeth.

37. This model only compares the relative degree of influence exercised by different people with respect to decisions affecting our health care system and medical decisions in general. It would be important to examine the factors which made up these degrees of influence, why each of the categories is placed in this order

and the variables in general which influence the decision process in health care and how these have changed over time. I have only generalized from our experiences and perhaps another study could examine the changes in the health care system in greater depth.

38. It is not my purpose to comment on the humanity of our Emergency physicians. I believe that they are fine and caring doctors. I only wish to emphasize that they are more administrative and government conscious than the physicians from previous eras. The real problem is that we have only X amount of beds available, a crowded and aging population waiting to be served and an overworked Emergency crew which is forced to release patients to home care.

39. I have only researched for correlations from ethics committee members. This may not reflect upon other physicians who are ethical and may still communicate well.

CHAPTER V

THE FAMILIES' SETTING

This chapter will be divided into four areas. First the discussion will focus on the debate concerning the value of families' involvement in the medical decision process. Should the doctor/patient relationship include the family or exclude them from any meaningful input into the decision process? The second area deals with the Jewish family in the context of the Jewish General Hospital (JGH). The family may have certain expectations from the JGH because it is a community-based institution whose historical goals and primary aims were to serve the Jewish community. While the Jewish General Hospital has moved from a private to a public government-controlled institution, I will show that the Jewish community still regards the Jewish General as a Jewish institution which has not lost its original identity. In fact, as the Montreal Jewish community moved to the right - religiously and philosophically - the expectations are that the JGH guard its identity and traditional goals while serving the community. Thirdly, I will examine some of the inherent Jewish family values and traits which families may express in their understanding of coping with life-threatening illness. These values include religious, cultural and psychosocial values and traditions. They are the baggage every patient and family, from every faith, culture and ethnic group, carries into the hospital situation.

Family Decision-Making

In examining the role of the family in the hospital and in the medical decision process, I have shown, in previous chapters, that families have been traditionally excluded from the doctor-patient relationship. This diadic relationship has been described as a contract and even a covenant between two parties.[1] In the view of many physicians, this relationship possesses a dogmatic aura, which has permeated the medical literature from its beginnings. It's almost as if there is a quality of sanctity to the relationship and it is somehow heretical to introduce the family to the decision process which belongs only to the doctor and patient. Finally, I doubt if there is any physician's code of ethics which does not stress the sacred confidentiality of the physician/patient relationship.[2]

There are, however, a few inherent problems in this private relationship. First is the problem of informed consent. While the physician may believe that a patient is fully competent, some patients may not have the capacity, or be borderline in their understanding of what the doctor is saying. I saw this in my physicians interviews, especially from Dr. C. Further, some physicians may intimidate their patients simply by their role as the "healing and wise" physician.

The second problem arises if the physician decides not to tell or to delay telling the patient a truthful diagnosis. The patient may not be ready to hear the truth. In the meantime, the nurses, social workers and chaplains who know the truth are caught in the middle so that they "break faith" with the physician if they share the diagnosis with the

inquiring patient. Thus, the standard response to the patient who insists on knowing the truth in such situations would be, "You have to speak to the doctor. It's really his/her department." In this situation, there is very little meaningful communication with the patient.

Finally, a different situation may occur when the patient is terminally ill and insists that his/her family must not be told. Sometimes the patient becomes depressed, stops eating or refuses all medication. The doctor, feeling uncomfortable, decides that the patient needs help from the family. An ethical dilemma arises, beneficence for the patient versus confidentiality. Some physicians are guided by their responsibility for confidentiality to the patient as long as they will not hurt others, such as in the case of an AIDS patient where others could be infected if the secret is honoured. Other physicians, such as many in our hospital, will "break faith" with the patient. First, they will advise their patients of their intentions to break faith and then speak to the family. These physicians believe that bringing harm to oneself is in the same category as hurting others and will, therefore, involve the family even against the patient's expressed desire not to involve them.

In reality, however, we have seen in the interviews that the physician/patient relationship is not as sacred as it is intended to be. Families are constantly advised, consulted and asked for their approval. Perhaps it has to do with the extremely busy physician or specialist who sees the patient for a few moments and has no time to develop a covenantal relationship or even a contractual one. It has become normal procedure to talk to the family. In all my years of chaplaincy, I have never seen the

family completely ignored. Physicians often disagree with families but I have yet to witness a scenario where families were not advised of the situation or were disallowed any expression of input towards the treating physician. The older physician-patient relationship has now evolved into a three way physician-patient-and-family contract. This is especially true and unavoidable in the case of the incompetent patient.

I now turn to examine some of the recent literature, which describes the advantages and problems associated with family involvement. I look first, historically, to examine the reasons why many physicians still express the importance of the doctor-patient relationship and why families should not be allowed in any decision process. I will then endeavour to examine these arguments in light of those who express a positive case for family involvement. Following these presentations, I will turn to my understanding of the Jewish family and then directly to my family interviews.

The Traditional Physician-Patient Model

Jecker and Schneiderman believe that we should be extremely cautious with families for they may be too emotionally or personally involved in the decision process. They cite the Wanglie case in which the courts agreed with Mr. Wanglie not to remove the mechanical respirator although Mrs. Wanglie was unconscious and declared to be in a permanent vegetative state. There was virtually no chance of recovery. Mr. Wanglie argued that Mrs. Wanglie told him "that if anything happens to me.... she didn't want anything done to shorten or prematurely take her life". Jecker and Schneiderman

wonder if Mr. Wanglie would have wanted this futile treatment for himself. They write:

> If this is correct, then Mr. Wanglie's request that *everything* be done for his wife did not express a genuine moral imperative, but may instead have expressed his "undying" love, or his desire to be a good and faithful husband.... Perhaps the treatments had become transformed from medical measures to emotional symbolism. Perhaps treatment had been diverted to a means of benefiting Mr. Wanglie rather than his wife, by postponing his own inevitable loss. Our point in raising these possibilities is to underscore that over and above religious, philosophical, or ethical reasons that underlie requests for futile treatments, psychological and emotional factors operate and have profound effects.[3]

Ruth Macklin also cautions along the same lines. She warns of the destructive family who interferes with the best interests of the patients. She writes:

> What families have is anxiety, fear, guilt, anger, hope and sadness. It is these feelings doctors have to contend with and that some mistakenly label as *rights*.[4]

Gilfix and Raffin argue that the popularization of advance directives through living wills and durable powers of attorney indicate an ambiguity and unpredictability in surrogate health care decisions made for adults.[5] The emphasis is to protect the rights of a patient by removing ambiguity and impossible criminal liability of surrogate decision-makers and physicians. If the document appoints a family member as surrogate decision-maker, then this family agent follows a standard of decision making known as substituted judgement. Many ethicists and legal authorities endorse substituted judgement to promote the patient's wishes and preference. The concept of a patient's best interests become secondary under the substituted judgment standard which is part and parcel of a legal document. Recent studies also raise serious questions if families have the ability to predict the preference of older relatives. These studies show that families are poor substitute decision makers and suggest that decisions made by families should be held in

check or supported more fully by independent evidence of the patient's own wishes.[6]

Zweibel and Cassel conclude that durable powers of attorney are less practical than personal living wills which would clearly state the patient's preferences and choices of treatment.[7]

The decision by the United States Supreme Court in the Cruzan case has also brought into serious question the right of family members to be surrogate decision makers. Nancy Cruzan was injured in a car accident in January 1983 and had since remained in a permanent vegetative state supported by a gastrostomy, hydration and nutrition. A lower court decision granted her parents' request to terminate treatment. The Missouri Supreme Court and subsequently the U.S. Supreme Court, by a 5-4 margin, revised this decision in June 1990. They ruled that families alone do not have complete autonomy for incapacitated relatives. Families have to show clear and convincing evidence of the specific recorded wishes of the patient. The courts held that the patient's wishes must be written and clearly spelled out in detail as in an advance directive or living will. The major reason was that surrogate substitute judgement is dangerous and could lead to abuse. Family members could be motivated by emotional and financial pressures and not do what is in the best interests of the patient.

There is also an emphasis on individual autonomy which would underline the need of independence and avoid any dependency on families. Thus, geriatric family members are encouraged to make their own decisions which foster personal growth and autonomy.[8]

Susan Erstling identifies some of the unresolved problems which may hinder any

meaningful family input. Marital conflict, for example, could prevent a spouse from making a fair decision for her husband. She may be fraught with feelings of guilt, hostility, or disappointment. Within parent-child relationships we often find stored-up feelings of rejection or anger causing feelings of self-reproach. These feelings are then expressed in over protectiveness and unrealistic wishes to prolong the life of the patient. There also may have been untimely deaths, a recent job loss, divorce, or a child leaving home. Thus, the family may be taxed to a degree that they feel helpless and cannot face any crisis situation.[9]

From my own experience, many patients give up the battle, stop eating and communicating as if to say "enough is enough". At this point, everything is left to the family. Sometimes it leads to a masquerade of shared decision-making by the family which officially serves "the patient's best interest" while causing discomfort and even pain to the patient. I also hear, "Rabbi, you can go into the room, but don't tell her she has cancer. Just go in and cheer her up." We sense the feeling of overprotectedness on the part of the family. In many instances these approaches are in the best interest of the family who are not ready to "let go".

The Physician-Patient-and-Family Approach

Although the traditional literature abounds with arguments for maintaining the sanctity of the doctor-patient relationship, a newer, albeit smaller, body of literature has developed which has welcomed the family into the decision process, especially in the

case of the incompetent patient. John Hardwig, in the landmark article titled, "What About the Family?" asks a simple question, "To what extent can the patient's family legitimately be asked or required to sacrifice their interests so that the patient can have the treatment he or she wants? This question is not only universally ignored, it is generally implicitly dismissed, silenced before it can ever be raised."[10] He adds, "To be part of a family is to be morally required to make decisions on what is best for all concerned."[11]

Because of this argument, Hardwig is uncomfortable with the two competing paradigms of medical ethics, the beneficence model and the autonomy model. He writes:

> In fact, I would argue that we must build our theory of medical ethics on the presumption of equality: the interests of patients and family members are morally to be weighed equally; medical and non-medical interests of the same magnitude deserve equal consideration on making treatment decisions.[12]

Hardwig has introduced a new element into patient autonomy and physician advocacy. The patient now has weighty moral responsibilities. If we do not want to recognize these responsibilities or burden the patient with them, we are abandoning the ethic of patient autonomy. And if the physician as advocate acts on behalf of the patient without consideration of the family, then we enter into a moral dilemma. The physician as judge of what is best for the patient is not only to be concerned about which medication to use but must try to harmonize and balance the interest of the patient and his family.

Hardwig's argument has important implications. In addition to the doctors' and patients' responsibility to consider their decisions in light of the ethical impact upon the

family, the basic concepts of confidentiality and truth-telling are at risk. Consider once again the treatable patient who refuses treatment, advising the doctor not to consult with his family. This is not an unusual case. The physician becomes uncomfortable. He may ask, "Are the rights of confidentiality absolute? Do I as a physician not have the responsibility to consider what is ultimately beneficial for the patient?" Can we imagine a scenario when a treatable patient died and the family discovered that the doctor purposely left them out of any decision or discussion?

Erich Loewy is another strong advocate for the family. He sees the struggle between an individual's autonomy and communal benevolence as between individual rights and social justice. The community would then serve as a vehicle to mediate and facilitate a common goal for a common good. Likewise, in the patient autonomy versus medical beneficence debate, the family could be asked to be a possible source of mediation. He concludes in his article,

> Individual wishes are formulated and enunciated in the interests of the family and likewise in the interests of the community. It is mistaken to conceive of *interests* as purely individual. The whole notion of what is and what is not *my* interest must and inevitably does take account of my context: my family, my friends, my students, and ultimately my community. In choosing a restaurant to go out to dinner, my wife's interest is not apart from mine: my interest includes her values and wishes. When I choose time to go on vacation, my students' needs form part of what can be called *my interests*. When I am ill or hospitalized, the needs of my family are part of the shape *my* interest takes. This is not an expression of altruism, but of fact. Interests rarely occur in a vacuum: to have an interest in anything almost always implies a community of others.[13]

Daniel Callahan, in his view of the family as caregivers, questions the limits of our moral expectations when we demand that the caregivers carry the social, physical,

moral, and psychological burdens placed on the family. Simply to be fair to family members at the risk of causing bitterness and anger only suggests that they should have a right to participate in the decision making process. Callahan writes:

> In some cases, caregivers must sacrifice their present and future welfare. That the moral claim made upon them may seem a justifiable one in many respects does not mean that it will be endurable; that it is endurable does not mean that it is justifiable. The problem is exacerbated by a lack of a supportive culture, one that rewards and honours those that take on heroic duties. Caregivers may be socially isolated.[14]

Thus it would seem callous to disregard the family. While a physician may argue, "My contract is with the patient. I am not treating the family and I am not interested in their wishes", such an argument seems unrealistic and even cruel in a society which demands so much from the family caregivers. It would be reprehensible to pick and choose our relationship with our family, use them when we need them while ignoring their input in any decision process.

David J. Doukas, in strong support of family involvement, has devised a contract, which he refers to as "the family covenant", which includes the family in the decision process. This covenant, signed by the patient, whole family and doctor, would transcend the concept of a contract between doctor and patient based on the honour of a covenantal promise. It involves an accumulated trust between the parties, recognizing that patients are attached to families and thus when we treat a patient, we must treat the family as well. As well as balancing "rights", it would also balance the responsibility to the patient considering the safety of others. While many ethicists[15] disagree with Doukas, they only challenge the viability and implementation of this model.[16] The concept of family involvement through contract or covenant is in itself recognized as important.

Loewy points this out,

> The tensions between family and individual views, needs, and desires can most certainly be reduced by a well-conceived plan: a covenant, preferably not one codified, but one in which trust and a sense of solidarity lead to a smooth functioning of the homeostatic process. The physician can act as facilitator, but the physician can and must not be the arbiter or final decision maker when value concerns are at stake.[17]

Dallas M. High takes four of the major arguments against family involvement as mentioned above: 1) the popularity of advance directives; 2) the importance of patient autonomy; 3) the research proving that families are poor substitute decision makers; and 4) that the decision in the Nancy Cruzan case questions the rights of any family involvement. High claims that there is empirical evidence that the elderly prefer family members to represent them in surrogate decisions. He refutes the argument through personal research that advance directives and durable powers of attorney were created to prevent difficulties with outside decision makers including families.[18] [19] [20] [21]

The major point High makes is that the emphasis on a legal document should not take the place of discussion and the communicative process between patient and family and physician. This argument is also emphasized by our own hospital brochure in preparing for any advance directives. It is the planning process and family communication which are most important.

The argument that individual autonomy is the foremost value for independent living is valid on a general level. However, when it comes to health care and decision matters, there should be a dialogue which includes family values. High writes:

> Almost every instance of decision making, especially health care decision making, is a process of moral dialogue grounded, either explicitly or tacitly in one's own basic moral community – the family. The current

> emphasis on autonomy as independence and avoidance of dependency may prove to be a dangerous tendency by drawing attention away from the appropriate balances and empowerment of human interconnectedness and interdependence that families provide.[22]

Marshall Kapp also reasons that sharing decisions is important for the elderly. First patient-family relationships contribute an empowering quality to autonomy to help think and act as opposed to the autonomy of being left alone. It is collaboration in supportive exercise in which the participants and their sense of control grow individually and collectively.

Second, there is also a desire of many patients, especially those in advanced years, to have a lesser need for information and control over health care decisions. Older patients also want to minimize the family burden of sharing decisions. This is an attempt to alleviate feelings of tension or guilt. Further, when independence is no longer feasible, interdependence between generations could stave off the choice of total dependency, which deprives the patient of all power and can only offer a façade of autonomy.[23]

With regard to the research of Uhlmann et al. and Zweibel and Cassell which show that spouses do not score well in predicting patients' decisions, the presumption is simply that family members should not provide any personal input because the substituted judgment standard, which permits the surrogate or family member to don the cloak of the patient, did not prove to be accurate. There are, however, contrasting studies which show that if we do not use a substitute decision standard model, but the best interest of the patient standard, we could reach a different conclusion than that espoused by Uhlman, Pearlman et al. We read:

> In contrast, studies conducted by Horowitz and colleagues (1991) concerning autonomy issues within family caregiving relationships found little evidence that families hinder autonomy or that conflicts of interest and goals occur with any significance. Their studies did not proceed on the assumption that surrogate decision making is best served by the substitute judgement standards. From explorations of four different measurements, the authors conclude that their findings support the policy initiatives that attempt to legitimize the role of family members as the most appropriate surrogate decision makers for incapacitated elders.[24]

High also replies to the decision of the United States Supreme Court case. In the case of Nancy Cruzan the Court ruled that families have no constitutional rights to act as surrogates for adult relatives on the basis that anyone could come forward with proof of the patient's will to refuse treatment. Therefore, families have no right to a presumption of surrogacy. High challenges this approach. "To reduce the role of families to acting as couriers of clear and convincing evidence from the patient, such as the patient's formally and specifically directed living will, is to denigrate the value of families and their good faith actions within the inter-generational interdependencies."[25] Even W.H. Colby, counsel to Nancy Cruzan's parents, concluded:

> We must remember that values, wishes, preferences and decisions do not develop in isolation from other persons, especially one's own family. Personal decision making including health care decision making is conducted mostly in a family context of shared values, wishes and preferences. Either to construe or imply that those relationships are irrelevant to the decision making process and the decision made is finally to force those who are family members to act as strangers to their decisionally incapacitated relatives.[26]

Finally, I turn to a benchmark contribution towards the importance of family put forth by James Lindemann Nelson and Hilde Lindemann Nelson in their book titled "The Patient and the Family".[27] They suggest an ethic of medicine and families which deals with the issues in this thesis and tries to bridge the gap between patient autonomy and

medical beneficence. A major contribution is their understanding of the ethics of the intimate and the values of intimacy. They claim that bioethics in contemporary moral theory is too impersonal. It does not take into account the personal, the human point of view. They say:

> If individualism, impartiality and universalizability are the general features of general theories of morality, the morality of intimacy can be characterized rather differently. Its leading features are collectivity, favoritism, particularity, non-consentuality and a pre-modern sensibility.[28]

Briefly, collectivity implies that the family is not only a group of individuals, but there are family traditions and practices which have distinctive significance for all family members. For instance, a sports-minded family may devote more effort, money and attention on a son who is a budding hockey star at the expense of other siblings. These traditions and practices become a collective responsibility. Thus, families may reply to a crisis situation in a particular way.

Favoritism is a natural force which permits us to be vulnerable to those we love and having that love reciprocated in special ways which makes us favourites. Love becomes a force which must be integrated into medical ethics. Love inherently plays favourites.

There are also elements of particularity to family ethics. Families define themselves through moral decision processes, developing a special feeling of solidarity and pride. There can be deep feelings of personal satisfaction. The family can develop a "name" for itself and thus respond to life and illness in a specific way. Families also define themselves through details of their ongoing history and develop a certain

character. These are important implications for medical decision makers.

Non-consensuality is the recognition of mutual family obligations that are delicate and often abused by family members. Sometimes power or imbalance of power within a family, prestige, resources, young versus old, sick versus well, the frail in the family whom families cannot support lead to mistrust, mistreatment and resentment. The concept of an intimate and even loving family does not deny that families sometimes rupture in trust. Family members feel bad when they are abused by other family members. There is a sense of betrayal of intimacy which is so hurtful and difficult to comprehend.

Finally, the Nelsons refer to a pre-modern sensibility which comprises an ancient concept of morality in families such as duties of parents to children and children to parents. It also includes special claims families have on each other's time, money and attention.

In view of the ethics of intimacy, the Nelsons developed seven values of intimacy which they refer to as stars by which we may navigate medical ethics. "We must neither ignore any of these values nor allow ourselves to be overmastered by any of them; either way lies ruin. What we now must do is to distill some of the general ideas about special moral significance about families into navigational aids - *stars to steer by* as it were - so as to help family members chart a safe passage among the rocks and shoals of contemporary medical practice."[29] I now list the seven values or stars.

1. Family members aren't replaceable by similarly "or better" qualified people.
2. Family members are stuck with each other.

3. The need for intimacy produces responsibilities.

4. Causing someone to exist produces responsibilities.

5. Virtues are learned at our mother's and father's *knees*.

6. Families are ongoing stories.

7. In families, motives matter a lot.

We can see the interconnectedness of the ethics of the intimate to the values of intimacy as espoused by these seven stars. I will note some of them as I go through my family interviews.

Increasingly, the issues regarding the family's role have become more complicated. Clearly, these issues cannot be easily resolved simply by invoking notions of patient autonomy or professional responsibility of physicians to their patients or concepts of beneficence. Neither can we reduce the series of issues to the simple dichotomy of an exclusive doctor/patient relationship or one that stresses the doctor-patient-and-family model. The issues are not simple. We have to listen and communicate. From my research I will note:

A) Family members are inherently involved with the care and concern with patient members of their families. (Nelsons' Stars # 1, 2, 3, 4.) However, they may not be thinking only of what is in the best interest of the patient, but what would be in their own best interests. (Nelsons' Stars # 6, 7.)

B) Patients and physicians may have different agendas. They may come from different backgrounds, socially, economically, religiously, culturally and linguistically. They may also see illness and death from different viewpoints and

communicate on different levels. (Nelsons' Stars # 5, 6.)

C) Sometimes patients and families are in disagreement or wish to hide information from each other. Some patients and families just can't come to any decision or have difficulties in coping with the present illness because of previous losses. In such situations, they will turn to the doctor, "Doc, do what you feel is best." (Nelsons' Stars # 1, 3.)

D) In other instances, the physician will turn to the family for final decisions. The physician may feel that the family knows the patient best and what the patient would have wanted at the end of life. The physicians, too, may have had recent similar experiences in their own families and would greatly empathize with the families' concerns. (Nelsons' Star # 7.)

E) Finally, I note that decisions are often made in a moment. When physicians are pressured to work quickly, it does not allow for dialogue. Both physician and families seek to trump each other in order to prove their point. The key is listening to each other, not trying to prove one's own position. We aim for winners on both sides. Indeed, a very difficult task.

The bottom line is that the links of communication have to be open. There has to be a capacity to listen and learn one from another, not to seek the last word or to use a trump card. There has to be a willingness on each side to hear all the arguments and resolve the issues. Only through this readiness and open communication can the issues be resolved.

The Jewish Patient, Family and Community in the Jewish General Hospital

As noted in Chapter IV, many of the physicians interspace their interviews with specific references to Jewish patients. One could almost expect a typical reaction from the Jewish patient community and their families. Because of these particular responses, I suggested another hypothesis which would state that Jewish families are very aggressive in their approach to treating illness and issues of futility. Further, because these contentious responses were pervasive throughout physician and family interviews, I thought it would be important to analyze them in order to better understand the Jewish patient and family in the hospital setting.

The hospital, as we shall see, is a source of pride to the Jewish community. Communal expectations include high standards of medical care. A result of these expectations is an actively involved and critical board ensuring that these standards are upheld. This attitude filters down to the individual family and patient. Because of these expectations, patients and families may be aggressive in their attitudes and communication towards the hospital staff. This section, therefore, will discuss this Jewish component of the hospital and its effect on the attitudes of Jewish patients and families.

In order to get a further glimpse into the psychosocial background of our hospital, I decided to contact some former executive directors of the hospital. It was my belief that Administration may have much to add along cultural and religious lines for it is they who set the tone and directions of the hospital. It is Administration which is responsible

for abiding by the hospital's mission and which must ultimately respond to the Board of Directors.[30] Administration deals globally with patient statistics, searches for trends, carefully watches the hospital's budget and decides on priorities and plans future strategies. It is Administration which creates the ongoing history and direction of the hospital. When I approached some of the former hospital executive directors, I asked them about the Jewish component of the hospital. They were eager to reply.

Mr. A. told me as follows,

> "Let me tell you something about the *Jewish*. We are a grass-roots hospital. True, our hospital is government-controlled but our community supporters and builders are average people. Unlike other hospitals who rely on corporations, banks, and big business for their support, we depend more than ever upon the lady down the block who is appreciative of our hospital's service and donates twenty-five dollars yearly and will hopefully have us in her will. This gives her a sense of belonging, feeling of membership and identity with her hospital. The hospital now becomes her domain. When she is hospitalized, she criticizes it, praises it and complains bitterly if anything is not to her liking. Our larger donors take it a step further. They expect something in return. It's cultural."

Mr. Sam Cohen, the first executive director, loved to tell this story. It was in the early days after the hospital was established - when hospital regulations prescribed certain visiting hours. Mr. Cohen relates,

> "I was walking down the hall of the main floor when I saw this elderly lady sneaking up the stairs towards patients rooms during the prohibited hours of visitation. I said to her *Lady, where are you going? Don't you know that the law says that you cannot visit during these hours?* She looked at me and said, *Listen Mister, I don't know who you are but this is my hospital. If I want regulations I go the Royal Vic or the Montreal General. But this is my hospital. I donate to this hospital and I will do as I please.* Mr. Cohen told me *Rabbi, I didn't reply. I was impressed by her answer. It was her hospital and she was proud of it.*

A similar viewpoint was expressed when Israel's late Prime Minister, Golda Meir,

visited President John Kennedy in Washington. President Kennedy reportedly told her that, "It is not easy to be President over 180 million people." Golda Meir replied, "Mr. President, you are President over 180 million people, but I'm Prime Minister over 3,500,000 million Presidents." I also think this phenomenon is not necessarily Jewish. Any ethnic group which would build its own hospital would probably express its pride in ownership, giving the group power to suggest change, critize and freely lend advice.

Dr. O, a specialist in Emergency Medicine, described it thusly, "There are ethnic differences which are quite notable and recognized by the staff. Oriental patients are stoic. They find it difficult to explain pain. You have to find it. They never agree to stay in the hospital unless there is no alternative. They keep their parents and aged grandparents at home. They have a strong sense of duty and respect for the elderly. Jewish patients are generally more aggressive, more demanding. They expect more. They don't like waiting, and want to see a doctor and be placed in a room immediately."

"Rabbi, it's amazing. In other hospitals it's different. I worked in the Montreal General for many years. There, Jewish patients were very polite. They were quiet, undemanding and generally model patients. But here at the Jewish, they feel at home. It's their hospital and they can complain, badger the staff, and sulk when they are told they have to wait."

Mr. Tom Czeisler, President of the Bikur Cholim Society (a religious Jewish group of visiting volunteers), explained it as follows: "The group of patients we visit are religious and Hasidic. They are extremely demanding. It's part of our faith. We'll spend thousands of dollars to save a loved one. Second and third opinions are the norm.

I help bring doctors in from the States. The more religious the patient, the more things are expected from the hospital. You must remember the case of Mrs. X, a young lady who was threatened with a double amputation. We got on the Internet and found three doctors who were willing to come in to see her. One was from England. We raised the money. The whole community gave. Everybody became involved. Dr. Andre Dascal in Infectious Disease was a gem. He not only cooperated but was there with her at all times. She felt it. We saved one leg."

"I get calls from families in panic. Tommy, you have to get my mother into hospital. She speaks little English. Please Tommy, a doctor that knows Yiddish. They think I'm a magician. Fortunately, many of our doctors know us. They help. Older people are easier to pacify. It's the younger ones that demand and expect immediate assistance. It's tough. There is an obligation to protect our parents. You ask from where does this attitude stem. *Honour thy father and mother even if your parents are unreasonable and unfair.* So how are we to behave when they are sick? We move mountains!"

In a further understanding of the JGH, an historical incident may give us additional insight into the psyche and mentality of the patients, families, physicians and the institution at large.

In 1933, the Jewish community went on a campaign to build its own hospital. These years were tough. Unemployment was high. Very few social assistance programs existed. Hospitals were private. The community rallied and in 1934 the Jewish General Hospital opened its 150 beds. There were two basic reasons for opening the hospital.

First, the community clamoured for a kosher hospital. Although Jewish patients were well-treated in other hospitals, they were uncomfortable with the food. Second, Jewish doctors who had graduated from McGill could not find positions. The Royal Victoria Hospital, St. Mary's, Montreal Children's and others were highly sectarian. They had the obligation to take care of their own Protestant or Catholic graduates. Further, in those days, Jewish doctors were considered lucky to be accepted in these institutions. The major English medical school in the province, McGill University, demanded higher marks and tuition fees from Jewish students. On the other hand, McGill as a Protestant university also felt obligated to protect its own. The Jewish community, however, felt that both the English and French discriminated against the Jewish doctors.

The landmark case which depicted the mood of this era and a prime example of this discrimination was the infamous Montreal intern strike of June 1934. Dr. Samuel Rabinovitch, who had finished at the top of his class at the University of Montreal, had been accepted as an intern at the Hôpital Notre Dame. Seventy-five interns from five different hospitals, including Notre Dame, St. Jeanne D'Arc, Ste. Justine, Hotel Dieu, and Misericordia, began Canada's first-ever doctors strike. The *Medical Post* of October 16th 1990 described this period as **Days of Shame**. Dr. Rabinovitch was forced to resign. His letter of resignation appeared in all the Montreal newspapers. "In view of the stressing, serious and dangerous condition to which the patients of the Notre Dame and other hospitals have been exposed because of the refusal of a number of their interns to take orders from their superiors.... I feel it is my duty as a physician to render my resignation to your hospital." In a later letter, he expressed his bitterness at "the direct

insult which the Jewish race had just received". He also said, "I feel deeply aggrieved that the French interns have taken up the racial question in a hospital where the care of the sick should be their first and only consideration."[31]

Le Devoir reported that the leaders of the strike "announced their intention of beefing up an already existing committee established by the archbishop of Montreal to investigate the *Jewish question* at the University of Montreal." A strike leader said, "the university authorities are the first to want to know if the university must receive Jews and why it is accepting them in such large numbers". The *Medical Post* reports that the reasons behind the strike were, of course, certain deplorable French Canadian traditions. There was the perennial religious bigotry of the Catholic church, who saw the Jew as a Christ-killer. With that was allied a sexual repression which produced phobic anxiety at the thought of a Jew touching a Christian woman.[32]

Have things changed in the past 65 years? Of course. Discrimination of this sort has passed. Politically, we are told that we are the finest country in the world, where freedom rings true. We even allow government opposition which would destroy our country. We are unique. Discrimination hardly enters the mind of most Jewish people, especially in our hospital community.

There remains, however, a local cohesion expressed on a religious and cultural level which has united the Montreal Jewish community. There is a debate whether this is due to a local unclear political situation which has separated ethnic groups from the mainstream French population or whether it stems from an inner strength which has been fuelled through an identity with the State of Israel. I believe it is the former. In either

case, I looked at some recent Montreal Jewish statistics and note that many of the traditional values remain strong. The Canadian Jewish Congress reports that Montreal has 55 Orthodox congregations versus 5 Conservative, 1 Reconstructionist and 1 Reform.[33] These figures are in almost direct contrast to other cities in the United States such as Los Angeles, Philadelphia, Dallas, and San Francisco where Reform and Conservatives have their stronghold and Orthodox is in the minority. In some studies made by the Federation of Jewish Community Services of Montreal, we learn that approximately 73% of Montreal Jewish children receive day school education.[34] When I went to school in the late 30s and 40s, virtually all Jewish children went through the Protestant School Board system. Further, approximately 64% of Montreal Jewry has membership in a synagogue or Jewish organization. This is among the highest on the North American continent.

We may ask, how do these figures affect and translate into the Jewish General Hospital? One major item is *kashrut*. It is the only Jewish acute care hospital outside Israel and a few in New York City which is fully kosher. From the 1980s until the present when government cut back hospital funding, it was up to the hospital to choose its method of reducing expenses. When the question arose of reducing dietary expenses, the Board knew that they were paying approximately $300,000 a year for keeping our hospital kitchen kosher. They calculated this by researching costs for other hospitals in the province with approximately the same six hundred beds. They noted a $300,000 difference in the dietary area. The hospital has two kitchens which serve only kosher meat and dairy products, which are more expensive. Within the framework of all the

various committees working on reducing expenses, I could still not envision cutting *kashrut*. The hospital would lose its identity without this service. Even the coffee shops and restaurants which primarily serve visitors have always been traditionally kosher.

Chaplaincy, too, feels the pressure from the outside. We run daily prayer services, High Holiday and Passover Seder and services. The complaints still come pouring in. "We aren't religious enough. We are not Jewish enough. How do I, as Head of Chaplaincy, allow men and women to be sleeping together in one room? How do we allow non-kosher food to be brought into the hospital by patients?" The complaints are endless, but this is from a very important and growing segment of our Jewish community.

The Jewish population in hospital still remains at about 35%. We may surmise that the outpatient clinics serve the same percentage of Jewish patients. The attending staff of 486 physicians is about 70% Jewish. Some of these are very Orthodox.

Another consideration may be the reaction of the elderly concentration camp survivors towards their choice of the Jewish General Hospital. Hospitalization for them may have a great personal psychosocial impact. Certain elements of hospital procedures such as loss of direct family contact, personal clothing, privacy, freedom, independence, decision-making, life and death decisions made by others, uncovering of body to others, penetration of body parts, loud instructions, even orders to shower and shaving heads - all these have high personal and intense symbolic meaning. At the Jewish General we are aware of these long-repressed and traumatic experiences and perhaps are better able to deal with them.

From my interviews, it is quite obvious that there is a specific cultural response from all faiths and ethnic backgrounds. I like to refer to the specific Jewish response as Jungian in origin, involving generations which always emphasize patterns of striving, seeking to do well in all endeavours. It stresses independence and has produced generations of over achievers. Futility is expressed in terms of "perhaps we didn't do enough", "maybe we should have called another doctor", or "Rabbi, they're abandoning her", "nobody does anything", or in cases of PVS, "how could we have agreed to starve her?". Sephardic patients are in general more emotionally involved than the Ashkenazic group. Most of my after-midnight calls are from Sephardic families. They often insist on rabbis being with the patient as he or she dies. Prayers are said, interspersed with emotional outbursts and crying. It's a cultural response found especially in Jewish families from Morocco. Many of the Sephardic families have pictures of their rabbis near the bedside. They have a profound belief in miracles, but this too is slowly changing.

There is another theory which I offer as Chaplain and former rabbi of a congregation. It is a personal thought and may not represent the feelings of the community at large. Generally, in Jewish synagogues, there is an unwritten rule; rabbis should not talk about life after death or the world beyond. This is not because it is not part of our faith. Maimonides considered it part of the Thirteen Principles of our Faith.[35] The reason is, I believe, that people don't want to hear about issues of heaven or hell, nor of sin and wrong-doing. A famous story among rabbinical groups involves the young rabbi who accepts his first pulpit. On the first Saturday he preaches about the

importance of the Sabbath - that Jews mustn't desecrate this holy day. The next Sabbath he speaks about morality and the family, lying and honesty in human dealings. On the third sabbath, he spoke of *kashrut* and how important it was to keep kosher both in their homes and in the community. The next day, the rabbi was called in to face the Board. "Rabbi, you are a good speaker and a fine young man. But we don't agree with your choice of sermons." The rabbi asked, "What would you want me to speak about?" "Speak about Judaism" they replied. "You know, to give charity, to be good parents, to be responsible to the community, to help one another, to be good human beings. Speak about Israel, the Holocaust, justice and injustice, and politics in general."

This scenario may be familiar to other faiths as well. But to rabbis, it has become the norm. We do not discuss death or life after death. We avoid it like the plague.

We may ask, "What does all this have to do with the subject of futility?". Simply this, if we do not discuss death, life after death, and the world beyond, families and patients learn to avoid it as well. They did not discuss the subject when they were in good health, certainly not now when they are ill. It's emotional, not logical. We, as rabbis and teachers, have avoided an issue that is part of life. The result is that we are not ready for issues of death and futility. This approach may explain why Jewish people may take the medically aggressive route. It would explain our disdain for the living will and palliative care which are not popular among Jewish families. It may also account for Mr. A.'s "grass-roots approach" towards the hospital after 65 years of its inception. When rabbis and leaders constantly speak of communal responsibility and the individual

responsibility to the community implying that life on earth, not life after death, is most important, then the community as a whole may feel the obligation to respond in kind, towards aiding the hospital in their efforts to save life.[36]

I have tried to show that the Jewish General Hospital is an insitution representing the Jewish community at large and may have an influence on the thinking, attitude and expectations of the Jewish patient. Just as one enters the hospital, he/she is immediately faced with a cafeteria, coffee shop and confectionary gift shop that is completely kosher, closed on Saturdays and all Jewish holidays. There is an ambience which makes the Jewish patient and family comfortable, if not physically, socially, psychologically and spiritually. And when the patient is unhappy, the question most often raised to me in Yiddish is, "Rabbi, what's going on? It's supposed to be Jewish hospital. Where is the heart? How come it takes so long for a nurse to come by? Where are the doctors?" I answer, "This is not the only hospital with shortages." Perhaps I'm asked these questions because I'm the rabbi. They want to impress me with their concerns. To whom else can they make these complaints? But in the end, we note the frustration. The expectations are there and the doctors, families and patients are sometimes disappointed.

Jewish Family Values

One of the most salient values observed was that Jewish families place great emphasis on being over-protective of the patient. It was almost as if the physician was

expected, at first, to report to the families the patient's diagnosis. Then the family and the physician would decide if, when, and how to tell the patient the prognosis. Second, physicians perceived a sense of aggressiveness on the part of the family. Families expected physicians and nurses to be constantly nearby when needed. Ofttimes they would seek second and third opinions.

I now turn towards an understanding of the Jewish family. Why is the Jewish family over-protective and aggressive? Why do they insist on leaving no stone unturned, moving from doctor to doctor seeking the answer they want to hear? Borrowing from the Lindemanns, I too offer a few stars to steer by. However, I will refer to these "stars" as values. For whereas Nelsons' stars stem from psychological and social entitities within the family, these Jewish family values originate from cultural traditions and beliefs. These values and traits are by no means the last word. I write in general terms which may help to understand the family as they confront our medical system, especially in the futile situation.

The first value is the major belief in Sanctity of Life. This is both a religious and cultural concept. From the religious view and especially for the Orthodox Jew, it is an overriding principle which is involved in every medical decision. It is the major religious concern in every medical issue.

A corollary of this principle is that Judaism regards every moment of life as sacred. There is no greater mitzvah than to save a person's life. The Talmud says, "to save a single life is like saving the world".[37] It is called the mitzvah of Piku'ach Nefesh (to save a living soul). Thus, in drawing a paradigm of Piku'ach Nefesh we

might say that when a person is drowning we throw him/her a life preserver. So, too, to our patient who may be deathly ill, we give a respirator which brings oxygen. Removing the respirator is the same as taking away the life preserver from the drowning person.[38]

The cultural aspect of Sanctity of Life stems from Jewish history and the perennial survivor syndrome. The Jew is the historical survivor and suggesting other than the Sanctity of Life is the exact opposite of the cultural Jew's *raison d'être*. It is almost unthinkable to deny a concept which is part and parcel of the cultural Jew's essence as a human being.

We may ask, "What of the Jews who were born in Canada and have acculturated to the Canadian way of life?" They may neither feel religiously or culturally inclined to their Jewish heritage. Sanctity of Life is not as important as quality of life. The doctor tells the family, "Look at mother, there is no quality of life. There is virtually no chance of any meaningful improvement to her way of life." The family agrees. This scenario is commonplace. It happens every day in our hospital. Some families may say, however, "But mother was religious" or "Mother was a Holocaust survivor" or "Mother comes from Israel. She would have not wanted to give up so easily. It would be against her beliefs." Families struggle. They may personally agree with the doctor but will do what mother would have wanted.[39] This latter group may be found in the Conservative, Reform and Reconstructionist branches of Judaism, or in families of second generations from Orthodox beginnings. Further, all groups may be personally very emphatic on the Sanctity of Life principle.

The second value to help us navigate the family system is that the Jewish family has an inordinate fear of death. I do not wish to imply that the fear of death, especially today, is not a universal experience.[40] The Jews, in general however, have not only an exceptional fear of death, but will fight death to the end.

According to the Jewish tradition and culture, we do not die easily. We rage and we storm. None of us needs Dylan Thomas's verse, "do not go gentle into the good night". It comes naturally. For the Jew, *Chayyim* (life) is the greatest blessing. When we raise our glasses to toast, we do not say "Cheers", we say *Le chayyim* (to life). Essential to our value system is the teaching of the rabbis in the following *Mishna*, "One single man was created in the world to teach that if any man has caused a single soul to perish, it is as if he has caused the whole world to perish. If any man saves a single person, it is as if he has saved the whole world."[41] To save a single life, one is permitted to break all the commandments of the Torah except prohibitions on murder, incest and idolatry.[42]

I am reminded of a story written by Y.L. Peretz, a Yiddish novelist of the early 1900's, who told how the sainted and illustrious Rabbi Israel Salanter acted publicly and dramatically in a crisis situation in the 19th century. The story titled, "Three Who Ate", describes the dire circumstances of the spread of cholera through Europe at that time. Yom Kippur has arrived and the main synagogue of the city is packed with worshippers who are fasting according to the Yom Kippur law. Rabbi Salanter, the Cantor and Shammas (sexton), all dressed in white as the law dictates, stand on the Bima (elevated platform and table in the centre of the synagogue). Rabbi Salanter announces that they

must break the fast in order to maintain their strength and resistance to the plague. At first there is a hush in the audience, then a murmur, and, finally, an outcry. "How can we do this on the holiest day of the year? The idea is totally unacceptable!" Rabbi Salanter quietens the crowd. He calls the sexton to bring him wine and food to the Bima and in front of all the worshippers, the three made a blessing over the wine and bread. They ate demonstratively in order to teach by their unequivocal action the religious law for that time and moment. It was not a matter of a relaxation in the Yom Kippur law. It became a religious imperative which demanded that the blessings be said because health reasons and the saving of lives supersede even Yom Kippur - the holiest day of the year.

Our greeting on Rosh Hashana (the Jewish New Year) is not only *Shana Tova* (Happy New Year) but *Leshana Tova Tikotaivu Vetaichatoainu* meaning, "May you be inscribed and sealed in the Book of Life." Tradition has it that God opens up the Book of Life on Rosh Hashana, and if he feels that we have all done well, our names will be hopefully inscribed in the Book of Life. In the Rosh Hashana prayers we recite, "charity, repentance, and prayer can avert an unfavourable heavenly decree". In the Orthodox and Conservative Jewish traditions we can hopefully avert the sentence of a terminally ill patient through special prayers and changing the name of an extremely ill patient. Since all our names are written in the Book of Life, we add a name, usually Chayyim, Chaya or Alter which all represent "life" so that any original bad decree will not fall upon the patient since he/she has now a new name.[43] This is the reason why most *Ashkenazi* (European) Jewish parents will never name a baby after a living

grandparent, because to do that would be tantamount to writing the grandparent out of history.[44]

In the Judaic faith, life is a gift from God. We are born in the image of God. We have to do everything to preserve life. Physicians and surgeons are held in the highest esteem because they have been given the power to save life. We read in the Talmud, "The school of Rabbi Ishmael taught *and he shall be thoroughly healed.* (Exodus 22:19) These are the words from which we learn that the authority was given by God for medical doctors to heal." In Ecclesiasticus Ben Sira 38:1/2 we read, "Honour a physician according to thy need of him with the honours due to him. Verily the Lord hath created him." I often joke with physicians who tell me, "Rabbi, I don't envy your job." I have a stock answer. "Doc, when you save a life, you are a better rabbi than I'll ever be because you are doing the greatest *mitzvah* in the world - saving lives."

The laws of mourning including the Shiva period (7-day mourning period) and Kaddish (prayer recitation for families who have experienced a loss) have been desribed as comforting rituals which psychologically allow the mourner a period of acceptance and closure with the deceased. It is a period of healing. Family and visitors come together to comfort one another. The Shiva period gives the family time to adjust and make plans for the future. However, it is also a constant reminder that a life has been snuffed out and that death has prevailed over life. It is as if the final chapter in the life of the deceased has been concluded. Jewish tradition teaches us that this should not be the case. The belief in an after-life is part of a Jew's faith. We mourn for the loss of a

loved one whom we will miss, but life must continue in full force. Mourning is only temporary. In fact, the *Shiva*, *Shloshim* (30-day mourning period) and *Yahrzeit* (11-month period) period all end rather with a fraction of the last day counting as a whole day.[45] This points to the principle of "Do not mourn over-much." At the end of the Shiva period, we leave our homes to walk "around the block" in order to remind us that we have to go back to society to do our work and obligations. We are not allowed to extend the Shiva period. The rabbis frown on all those who mourn more than necessary.

Earlier in this thesis, I also pointed to the fact that rabbis and their congregants avoid the subject of death. The baffling part of this phenomenon is that it is the exact opposite of Judaism's traditional beliefs and culture. The Code of Jewish law emphasizes that when serious illness strikes, the patient should be ready to face his maker and say the *Vidui* (confessional prayer).[46] This Vidui prayer was an acceptance of death and was always an important part of our faith. In previous periods of Jewish history, natural death was an accepted way of ending one's life. The expression, "the Lord giveth and the Lord taketh away. Praised be the name of the Lord", was on the lips of every grieving Jewish family. Ironically, in direct contrast to the tradition, many Orthodox families will not accept death easily. They often avoid me or advise me not to go into the room for it may frighten the patient. Quietly, families contact their own rabbis or Hasidic rabbis for blessings of good health. They do not burden the patient with these thoughts. Even discussions about death are avoided by many religious people. The patient may have a metastatic cancer but to talk about death is a bad omen. I sometimes hear, "Rabbi, we are a religious family and have full faith that God will cure my father.

We don't talk about death." I do not say anything, but this is far from faith as we were taught. More appropriately, a religious family would say, "Rabbi, we have faith and we pray for the health of father, but the good Lord will do what He pleases."[47]

Personally, I have had a few most distressing experiences in the area of *Bikur Cholim* (patient visitation). When I first started chaplaincy, I spoke openly with the patients. This was part of my training. The families did not appreciate it. One family escorted me out of the room. "How dare I talk to father about Vidui. Please do not come back again to visit." These episodes did leave their mark. My style changed. Presently, when I go to rooms, I try to encourage the patient, not by any untruths, but to have hope for a better day. The families, I believe, appreciate it. However, when I ask the patient if he/she wants to pray with me or if they want to talk to me privately, many families get upset.[48] It's different if the patient is comatose. Families do welcome prayers in these circumstances. They are very protective, as the physicians pointed out.

The Sephardic patients and families, especially those coming from Morocco, have different expectations although they, too, are very protective of the patient. They are more candid about the illness and encourage the rabbi to come in to say a prayer and bless the patient, but "please do not talk to the patient about anything associated with death". After the demise of the patient, both Ashakenizic and Sephardic families appreciate proper prayers.

The third value is taken from the fifth of the ten commandments, "Honour thy father and mother".[49] Closely associated with this commandment is the verse which

tells us to "Honour the elderly".[50] Most faiths have also adopted these principles but there are problems. We live in a family-fragmented society where obsolescence is a built-in dynamic, a fact of life. Time is precious, a concept to be controlled and quantified. Productivity is the yardstick for a meaningful life while grandparents and sometimes even parents appear as anachronisms. The best years of their lives are perceived to be a thing of the past. They are outdated, old-fashioned, and have become a burden to society.

I recall a wise elderly patient who told me, "Rabbi, I'm an old man living in a computer age I don't understand. What can I tell my children and grandchildren who are living in this world of computers of which I know nothing about?" I replied, "Why is computer science so different than any knowledge that you know nothing about? There have always been scientific breakthroughs which separated generations." He answered, "This is more than knowledge. Computers are equated with productivity. You could hardly make a living unless you are acquainted with computers. An old man like me is truly ancient." I did not agree, but I wonder if many of our elderly geriatric patients really feel this way.

Parents are regarded, as Linzer points out, as symbols. "Parents serve as a medium through which children enter the Jewish world of faith, ideals, history and community leadership."[51] Perhaps we could argue with Linzer saying that this in itself is an ideal but in reality Jewish families are not interested in faith, history or community leadership. Linzer, however, may have a point. There is a sense of tradition and history in most families. Parental authority automatically includes a family tradition. We note

this from the birth of every son who is circumcised as a Jew. The son enters a covenant which goes back to the time of Abraham. It is a symbol of Jewish identity and history. Hartman says, "The *Brit* (circumcision) is a symbol of Jewish identity; a person is not defined by genetic constitution alone, but by norms and ideals."[52] Thus Jewish people of all beliefs and backgrounds, from the Orthodox to the atheist, will perform this *Brit* ceremony.[53]

Blidstein refers to the fifth commandment as an ethos of gratitude. Children give respect to the parents because they gave them life and struggled to provide and teach them moral values.[54] But at the same time, parents were real people, authority figures who succeeded and failed, responsible for providing the material and psychosocial and spiritual needs of the children. This was not only a responsibility, but often a burden. The upshot was the establishment of the family and its inherent responsibilities and challenges. Within the family, you could also find a value system including a sense of identity and tradition. The generation which immigrated from Europe always boasted of their families. It was as if there was a need to talk about their families. Invariably, I would hear, "Rabbi, in Europe we had a large business" or "I came from an aristocratic family" or "Rabbi, I come from a long line of rabbinic families. My grandfather was a scholar. I do not come from a *proste* (unlearned and uncouth background) family. We were very highly respected." In the present situation, children speak of their filial responsibility and how they are fulfilling it. They speak of their concern and love for their parents and if the children are from out of town, they are concerned that their parents should have professional sitters, people taking care of them. The obligation is

there. There is a need to show how they care and shoulder their responsibility.

The fourth value expresses Jewish families as a group of high achievers, a phenomenon found among many immigrant ethnic groups. Many children from second generation immigrant parentage may recall being admonished by their parents, "What are you going to be when you grow up - a tailor, or a shoemaker like your father? God forbid! You are going to be a doctor, lawyer or engineer. You are going to make something out of yourself." The eventual upshot of this admonition was the invention of the joke, "my son the doctor (now expanded to - my daughter the doctor)".

I recall a personal episode from the fourth grade. I was a quiet kid, did my work and was generally obedient. One day in class, the teacher stepped out for a moment. Pencils and spitballs started to fly. There was one kid I despised. I let him have it with a pencil on the back of his head. The kid faked pain. At that very moment, Miss Jones (not her real name) came back and caught me red-handed. "Myer, tomorrow, two hundred lines - I will not throw pencils in class anymore." She wrote it on the blackboard. My friend's pain subsided with a smile. Tears welled in my eyes. Virtually, the whole class were throwing things at each other, but I was caught. I came home and complained bitterly about why I was singled out. My mother said, "no excuses, you deserved it. She should have given you double. I don't want to hear any more excuses." These expressions accompanied me right through school. "No excuses." "The teacher is always right." Another saying was, "So who told you life was fair? Go do your work."

The jokes such as "my son the doctor" were used to self-ridicule the status

seeking Jewish parent. It reflected a strong central family value of higher education and professional achievement. In most Canadian-Jewish families, children were expected to enter university. Parents would scrimp and save in order to send a child to college. Families would go to great lengths to deny or hide the fact that one or more of their children was unable to succeed academically. They would be embarrassed by the thought. If the child was a slow learner or - heaven forbid - mentally retarded, families would try to hide the truth from neighbours and friends. This era, however, is slowly passing.

Financial success is also highly valued. Although Jewish attitudes towards financial success are often stereotyped in novels, the historical reality is that experiences of anti-semitism have pushed them to strive harder to achieve independence and security. Although many Canadian Jews do not consider the notion of anti-semitism as a powerful force in their lives, I do note how strongly they react to any new account or incidence and to personal instances of perceived anti-semitism. This value is especially realized by Holocaust survivors and their children, something which many families experienced in our own time in this city. There is a pride in having succeeded in business in Canada. They emerged from a European hell, refugees from concentration camps without a penny to their name, and they made a success in Canada.

There was, however, danger in these demands for intellectual success and financial achievement. It often generated a feeling of failure no matter how much was accomplished. It was never really enough. Thus, in the medical situation, families place the physician under unfair and unrealistic pressures. On one hand, he is a physician, but

only a family practitioner. How come he is not a specialist? If he's a specialist, why not Head of the department? If he's Head of the department, how is it that he couldn't cure the patient? Perhaps, he should have gone into research as well. It's almost as if you can't win. The result of these attitudes is a sense of failure and guilt which pervades the professional. He is never able to reach his goal; "my son the doctor" can only be a first step in the never-ending push to succeed.

A fifth value which may light our way stems from the old Jewish expression, "you have to be a mensch". The term "mensch" means a man. In one sense, one may think it's a call to being macho, but in the Jewish sense it was anchored in moral teachings which taught decency, sensitivity to others, respect for the law and a strong sense of responsibility towards family. Being a mensch meant doing the right thing - to have a sense of justice, honour, and duty. I recall my mother clapping her hands in exasperation to each of her children, "when will you become a mensch already?".

The difficult part of being a mensch is that we are taught by our same teachers, parents and peers that it's a tough world out there. It's important to get into the right school, to have the highest grades, and get the best paying job. It was nice if you could start your own business, but above all, you had to succeed. And although it may not be expressed in a blatant fashion, children and young adults got the message. They learned values from their parents who have, perhaps, struggled and hoped that their lives would have been much better if they had succeeded intellectually and financially.

We do not place the blame solely on our parents. Society has to answer as well. Our schools often foster a cynicism, a moral relativism and permissiveness that does not

make us proud. There are cultural forces such as television, internet, magazines and movies that have a profound effect on all families. Parents pursue dual careers, often addressing their own selfish motivations in high sounding moral language to the detriment of family and societal values. The result lends to confusion, guilt, aggressiveness and argumentative attitudes. Thus, families and children want to do their utmost for their aged parents in hospital. We have to be menschen. We have to be responsible and extend ourselves beyond, not only the letter of the law, but even beyond our normal capabilities. Our parents have to know that we tried like hell for their welfare. They trust us and we have to respond as menschen with sensitivity and not, heaven forbid, with callous indifference. Physicians are strangers who will forget the patients. We are the children, the menschen who will never forget.

Observations of Contemporary Jewish Families at End-Of-Life Situations

I earlier pointed to a change in thinking among Jews born in Canada having been acculturated to the larger Canadian scene.[55] I argued that if this group were taking care of their parents who were of a religious background, from the old country or Holocaust survivors, they would not go against their parents' wishes, even if they themselves differed in their thinking about what should be done at the end of life. There are, however, many older Jewish people who are native born - secular Jews whose attitudes are more contemporary than the previous generation. They are more accepting of death. Palliative care, once categorized as a non-Jewish concept, is now being validated as a

proper approach for those who are in the last stages of life. Jewish hospice movements have been organized by rabbinical groups in the belief that there is a religious Jewish component to hospice since death is inevitable and it must be regarded as a religious experience. These groups exhort us to return to our roots, accepting death as our forefathers did in biblical times.

But these changes in thinking, as modern families would like to believe, are slow in coming. There still remains strong vestiges of the past. It is as if there is an internal struggle against accepting death. Logically, we argue that death is inevitable and that a moment should arrive when we say that the battle is over. Historically, and from our tradition, death was always accepted. Existentially, we still don't accept it. It's like the surgeon who once warned me, "Rabbi, get ready! At the "Jewish", patients never die a natural death. Somebody goofed and the patient died."

In trying to analyze this particular Jewish struggle with accepting death, I suggest the following reasons[56]:

1) The claim made by physicians in hospitals that, by using modern medicine, they can perform miraculous, amazing feats of healing. This claim is widespread. The feeling may be intensified by the great respect Jewish people have for physicians. (My son the doctor.) There is also an immense pride the Jewish community has in establishing their own hospitals in communities the world over. The biggest mitzvah was to save a life.

2) The willingness of Jewish families to turn their elderly family members over to the care of hospitals. Instead of fighting to keep their dying or sick family

members at home, in the midst of their loved ones, Jewish family members have rushed to deliver them to hospitals. Perhaps this "rush" reflects their traditional commitment to the sanctity of life, combined with a faith in modern science. Perhaps it reflects their own fear of feeling guilty for not doing what could be done. In any case, they especially seek to gain hospital care. This would lead to another specific Jewish family trait. Jewish families may be guilt-ridden just by placing parents or their loved ones in hospitals or nursing homes and not taking personal care of their welfare at home. This is especially noted by the son or daughter who lives out of town, rushing in to take care of mother, invariably arguing "that everything must be done to save Mother". In hospitals we are always aware of this out-of-town syndrome characteristic of family members who are not the caregivers of the patient.

3) However, once having had their members admitted to the hospital, Jewish family members are then placed in a somewhat difficult paradoxical and uncomfortable position of seeming at once to be caring for and abandoning their family member. (Abandoning them to the hospital.) This setting, no doubt, may aggravate feelings of guilt and tension between family members and their patient members. Family members should, by tradition, be caring for their patient members, but they have seemingly turned this job over to someone else. To be sure, they can visit regularly. But this situation of doubt gives rise to a number of contradictory, uncomfortable, often not fully examined and not easily examined feelings.

Further to the above specific Jewish responses are universal concerns which may be additional factors that have to be taken into account. These include our natural instincts which would deny our mortality and that our death-denying society is partly based upon a medical system which emphasizes the most up-to-date life-saving equipment and a staff which is in constant battle with death.

There still remains, in my opinion, a Jungian cultural and psychologic response which emphasizes the principle of the sanctity of life. Further, many of us have lived through or even endured the Holocaust era. We witnessed the struggle of the birth of Israel and the many wars the State has had to fight to maintain its existence. All these add to this specific response, even if we haven't experienced the Holocaust or fought in the Israeli wars.

Finally, we still have to cope with the natural fear of death, the fear of the unknown. Becker claims it's a natural response, the denial of death. Our religions offer faith, little proof of an after-world. Death to most of us is an existential fear of annihilation. It's a battle.

Conclusion

In this Chapter I have endeavoured to introduce the Jewish family setting of end of life situations. I began by examining the literature on how physicians view the family in the context of the patient. Should families be permitted to have any major input which may upset the traditional physician/patient covenant? Second, I examined how patients

and families see the role of the hospital towards terminally ill patients. I offered an overview of the hospital's history, how the Jewish community responds to "their own" hospital and the perception and expectations Jewish patients and families may have towards how the hospital will treat them at the end of life. Third, I examined Jewish family values and traits as they pertain to the families' attitudes in end of life situations. I offered a list of six traditional Jewish values which light the ethical landscape and give insight to how we understand and assess families. We try to recognize what illness means to the family and how they cope with it. We can now demonstrate that we know their concerns and culture while we try to tap into their strengths. Above all, we can realize the importance of good communication and how to reach the families in an appropriate and hopefully successful manner. Finally, I discussed contemporary beliefs and the tensions and difficulties Jewish families have in dealing with the older values and modern issues confronting older patients at end of life.

My next chapter deals with the family interviews and the families' perceptions of the physicians' approaches to the futile situation. I will discuss how the families perceived the physicians' communication with them and the physicians' expectations of the family in this situation. I will also connect and demonstrate how the six Jewish values are presented in the family interviews. I will note differences between the physician and family responses and offer a critique of the families' responses. I will then assess the families' responses in terms of the values. Finally, I will analyze the responses and values and explore which values were most important to the families.

Notes

1. Wiliam F. May, "Code, Covenant, or Philanthropy", *Hastings Center Report* 5, no. 6 (1975): 33. May explains that a contract deals with fulfilling the specific obligation by mutual agreement while a covenant includes a trust over time between the parties and allows responsiveness to situations that a contract alone could not foresee.

2. See Appendix B for Code of Ethics, *Canadian Medical Association*, sec. 22.

3. Nancy S. Jecker and Lawrence J. Sneiderman, "When Families Request that Everything Possible be Done", *Journal of Medicine and Philosophy* 20 (1995): 145-163.

4. Ruth Macklin, Mortal Choices (New York: Pantheon Books, 1987), 38.

5. M. Gilfix and A. T. Raffin, "Withholding or Withdrawing Extraordinary Life Support", *Western Journal of Medicine* 141 (1984): 387-394.

6. R. F. Uhlman, R. A. Perlman and K. C. Cain, "Physicians and Spouses Prediction of Elderly Patients Resuscitation Preferences", *Journal of Gerontology* 43 (1988): M115-M121.

7. N. R. Zweibel and C. K. Cassel, "Treatment Choices at the End of Life: A Comparison of Decisions by Older Patients and Their Physician Elected Proxies", *The Gerontologist* 29 (1989): 615-621.

8. J. W. Rowe and R. L. Kohn, "Human Aging: Usual and Successful", *Science* 237 (1987): 143-149.

9. Susan Erstling, "The Shared Burden: When Physician and Families Decide to Forego Life Sustaining Treatment", *The Journal of Family Practice* 20, no. 4 (1985): 393-399.

10. John Hardwig, "What About the Family?", *Hastings Center Report* (March-April 1990): 5-10.

11. *Ibid.*, 6.

12. *Ibid.*, 7.

13. Erich H. Loewy, "Families, Communities and Making Medical Decisions", *Journal of Clinical Ethics* 2, no. 3 (Fall 1991): 152-153.

14. Daniel Callahan, "Families as Caregivers: The Limits of Morality", *Archives of Physical Medicine and Rehabilitation* 69 (May 1988): 323-327.

15. E. H. Loewy, 151.

    Fred Rosner, "A Breakdown in the Family Unit", *Journal of Clinical Ethics* 2, no. 3: 148-149.

16. David J. Doukas, "Autonomy and Beneficence in the Family: Describing the Family Covenant", *Journal of Clinical Ethics* 2, no. 3 (1991): 145-148.

17. E. H. Loewy, 153.

18. Dallas M. High, "All in the Family: Extended Autonomy and Expectations in Surrogate Health Care Decision Making", *The Gerontologist* 28, 28 Suppl. 46 (1988): 46-51.

19. Dallas M. High, "Standards for Surrogate Decision Making: What the Elderly Want", *Journal of Long-Term Care Administration* 17, no. 17 (1989): 8-13.

20. Dallas M. High, "Who Will Make Health Care Decisions for Me When I Can't", *Journal of Aging and Health* 2 (1990): 291-309.

21. Dallas M. High and H. B. Turner, "Surrogate Decision Making: The Elderly Familial Expectations", *Theoretical Medicine* 8 (1987): 303-320.

22. Dallas M. High, "A New Myth of Families of Older People", The Forum, *The Gerontologist* 31, no. 5 (1991): 613.

23. Marshall B. Kapp, "Health Care Decision Making by the Elderly: I Get by with a Little Help From My Family", *Gerontologist* 31, no. 5 (1991): 619-623.

24. Dallas M. High, "A New Myth of Families and Older People", 614. High refers to the study of A. Horowitz, B.M. Silverstone and J.P. Reinhardt. "A Conceptual and Empirical Exploration of Personal Autonomy Issues Within Family Caregiving Relationships", *The Gerontologist* 31 (1991): 23-31.

25. *Ibid.*, 615.

26. W. H. Colby, "Missouri Stands Alone", *Hastings Center Report* 20, no. 5 (1990): 5-6.

27. Hilde Lindemann Nelson and James Lindemann Nelson, The Patient and the Family (New York: Routledge, 1995).

28. *Ibid.*, 63.

29. *Ibid.*, 73.

30. See Appendix C for the Jewish General Hospital's Mission Statements.

31. *Medical Post*, 16 October 1990, 12.

32. *Ibid.*, 12. Also see, the *Montreal Gazette*, 18 June 1934, 1.

33. Canadian Jewish Congress National Synagogue Directory (1998-99): 2-7.

34. This figure does not include the Hasidic schools which are not part of the Jewish day school system. There is an estimated 4,000 children in these private schools.

35. Maimonides, Commentary to the Mishna, Sanhedrin, Chapter 10.

36. My theory and rabbinical story above touches upon the purpose of a sermon. Is a sermon made to make its listeners uncomfortable, or, is its purpose to be intelligent, interesting and comfortable in order to attract people to the synagogue? The answer is probably somewhere in between.

37. Talmud Bavli, Sanhedrin 37A.

38. This may not be a perfect analogy. It could describe, however, how many Jewish families feel. Further, this analogy is not always halachically valid. There are times when we must allow the patient to die in peace. My thesis, however, does not cover the halachic aspects, but only the perceptions of and communication between physicians and families. For a further view on Jewish attitudes towards life and death, see David Novaks "Judaism", Encyclopedia of Bioethics, ed. W. Reich (New York: Simon and Shuster, 1995), 3: 1301-1308.

39. This is in direct contrast to Jecker and Schneiderman's argument, mentioned earlier, stating that Mr. Wanglie would have perhaps never wanted to be treated aggressively himself. Thus, it was hypocritical on his behalf not to remove his wife from the respirator. While it may have been an emotional factor whose purpose was to postpone his loss, in my experience, seeking what the patient would have wanted is a natural and sensible approach.

40. Philippe Aries, The Hour of Death (New York, 1981), 28.

    Ernest Becker, The Denial of Death, Chapters 1, 2.

41. Mishna, Sanhedrin 4:5.

42. Talmud Bavli, Sanhedrin 74A.

43. I have also witnessed Jewish people from the Reform and Reconstructionist branches turning to this tradition. The bottom line is that we have to save the life of the patient.

44. Since the baby has his/her name in the Book of Life which is the same name as the grandparent, the grandparent's name in the Book of Life is now expendable. The Sephardic tradition encourages the naming of a child after a living grandparent. It is considered a great honour. The Sephardim will also add a name to the patient in cases of life-threatening illness.

45. In other words, the first seven days are only 6 and a fraction of a seventh day. The *Shloshim* is counted as 29 and a fraction while the *Yahrzeit* of the first year is only 11 months with only a fraction of the last day.

46. Code of Jewish Law. Yoreh De'ah 338:1, 2.

47. Some Jewish people will also shy away from making last wills and testaments. It's supposed to be a bad omen. This is fairly common with Sephardic families.

48. Perhaps many of our physicians have adapted this softer, more helpful approach because of similar responses by the family.

49. Exodus 20:12.

50. Leviticus 19:32.

51. Norman Linzer, The Jewish Family (New York: Humane Sciences Press, 1984), 69.

52. David Hartman, Joy and Responsibility (Jerusalem: Ben-Zvi-Posner Company, 1978), 79.

53. Professor Margaret Somerville, ethicist at the Centre for Medicine, Ethics and Law at McGill has been an outspoken proponent against *Brit* circumcision. Her concerns are almost outlandish in a community which has treasured the ceremony for thousands of years. Jewish parents are embarrassed if they do not have the ceremony. In Dr. Somerville's latest book, The Ethical Canary, she retracts from her position if the *Brit* is performed for religious reasons.

54. Gerald Blidstein, Honour Thy Father and Mother: Filial Responsibility in Jewish Law and Ethics (New York: Ktav Publishing House Inc., 1975), 8-19.

55. p. 251.

56. Based on conversations with F. Bird.

CHAPTER VI

INTERVIEWING THE FAMILY

Family interviews took place at various times. Some were interviewed partly before and partly after the patient's death; some only after death. Three of the interviews were structured according to my original plan where I would meet with the families and doctors soon after the bad news had been told to the family. My main goal was to see how families perceived the communication in the physician-declared futile situation and how better patterns of communication could be developed.

Many families were anxious to tell their story. In hospital, interviews brought out concerns of confidentiality. "Will the doctor find out what we are saying?" Interviewing them after death in their homes or places of business made them feel more at ease.

I offer a word about my definition of "family". In some cases, "family" was the whole immediate family. Other interviews involved only the major family caretaker. I had many occasions to visit with families during the *shiva* (seven days of mourning) at their homes. During this time, I set appointments. I was never refused. Oft times, I would get the background to the case while visiting during *shiva*. Families would tell their stories to visitors and I would listen.

I did not have a fixed methodology in finding families to interview. I knew many

of the families. Sometimes I would go to the synagogue and there would be some gentlemen saying *Kaddish* (specific prayer for mourners). After services, I would ask them if they and their families would be willing to be interviewed. In many instances, I did not know the people. In this sense it was a random selection. On other occasions, I approached the family or phoned them asking if they would be willing to be interviewed. These were usually families I knew who had some difficulty communicating with the doctor in their end of life hospital experience.

Some of my interviewees were older families - others young. Some quite affluent - others not so affluent; some from children of concentration camp survivors - others from parents born in Canada. Some families were college educated and could understand and communicate easily; others were not. It was a mixed bag. The variables are almost endless. I did not question the families or their spokespersons whether they were personally involved in crisis situations other than the impending death of their relative. No doubt, this may have had an impact on their replies. There are other variables such as the suddenness or prolonged period of the illness and what do we mean by "prolonged". Was the patient fully or partially competent or completely incompetent, a victim of Alzheimer's or in a coma? Was the patient religious or secular, old or young? I did not go into these specific questions. Perhaps they belong to a further descriptive study which would zero in on specific types of families. I did, however, try to take a cross section of patients and families from all the above.

When I interviewed the physicians, I expected the answers of professionals. As the patient and family meet the physician, the physician is expected to fully play the role

of the physician who will diagnose and treat the patient. One could also divide the physicians according to variables, many similar to those within families such as if they are religious, secular, or in personal crisis. I believe, however, that families are more complex. They consist of individuals who have no specific professional role to play. They are humans with strengths and frailties who were confronted with a difficult and sometimes terrifying experience which can paralyze thought and action. My purpose was to generally examine the feelings of Jewish families in the futile situation in a hospital setting. I wanted to examine their experiences, their communication with physicians in a hospital milieu that is becoming more and more controlled by government. Perhaps I would be able to identify some of the threads, markers and values which are important to understanding the Jewish family and their expectations from physicians and the hospital staff in the medically futile situation and how communication could be improved.

Prior to the impending death, in the majority of cases, families are called to a meeting with the staff. Present are the doctors in charge, a resident, head nurse, social worker and the family. The families are apprised of the situation. It usually doesn't come as a surprise, although there is still a shock to the family. There is a sense of finality. "The doctor said it was futile to continue." The family then hears some explanations and suggestions. "We don't think we want to prolong this situation. We assure you that we will keep him/her comfortable and out of pain. We want to ask you, under these circumstances, should we resuscitate him/her if it is necessary?" The family is not really prepared to answer. They are given time. Quite often I get a call. "Rabbi, what do you think we should answer?" The process has now begun. How it will play

out depends upon the major players, the doctor and the family. The family members look the doctor squarely in the eye. The doctor in turn is usually sympathetic. The nurse and social worker may embrace the family members trying to be supportive.

I now turn to my research on the family. I asked five basic questions:

1. Tell me your story. What exactly happened with your mother/father?
2. When they told you the bad news, did they tell the family first or the patient?
3. Do you believe doctors have the right to end treatment in a medically futile situation, or can the family insist on further treatment?
4. If the doctor disagreed with you, how would you respond?
5. In cases of an impasse, who should have the final say?

As I began the interviews, I soon realized that my research led to four different types of responses. The first and most common response was that the family had no complaints with the communication nor with the outcome. The doctor explained the futility of the situation clearly. "We understood everything he/she said and agreed that there would be no further aggressive treatment." Simply, "Mother should be left to die in dignity without pain." Depending on the type of illness, this decision usually included DNR orders, removal of a respirator, discontinuing drugs or artificial feeding. The second group complained about the communication but when the futile situation arose, they concurred with the physicians to remove all life support. "We are not crazy about the doctor, but we are in agreement with him/her with regards to Mother's situation. She should be allowed to die because it is a futile situation and we do not want to prolong death." The third group were very satisfied with the communication but had

misgivings about leaving mother to die. "It's just not right. We have to try everything and we mustn't give up." The fourth group were completely dissatisfied. They battled constantly with the medical team. Generally, they did not like the physician's mode of communication or any decision to call the situation futile.

There are, however, shades of grey in every category. When I interviewed families after death many, in retrospect, changed their views. The month or six weeks after death gave them time to reflect. "Perhaps we were hasty in listening to the doctor." "Maybe we should have asked for a second opinion." Or, "Maybe we should have tried harder." "Perhaps we should have waited a few days." On the other hand, I heard, on occasion, "Perhaps we *mutchid* (mistreated) our mother." "Maybe the doctor was right. We only prolonged her misery." I would also hear, "We didn't understand the seriousness of the illness. The doctors didn't explain. She went so quickly." "We really didn't understand what the doctors were saying. They seemed so technical and we were paralyzed."

The examples which follow are taken from the fourth category where arguments and disagreements were prevalent throughout the patient's stay. The reason I chose this category is because it offers a better understanding of how families view the communication and of their different perceptions of futility. Their arguments will include those from categories two and three, giving us a picture of the problems in general.

I end the following section with one example of how a family described good communication and experienced a meaningful end of life episode for patient and family. My purpose is to show a contrast between good and bad communication which is so

evident and striking. It makes one wonder about the argumentative nature of human beings, their lack of common sense and the power of good communication.

The Family of Mr. A

Mr. A, an elderly 80-year-old Yiddish-speaking gentleman, was flown in from Florida having difficulty breathing and was diagnosed as having a serious case of aspirated pneumonia. He was admitted to the ICU and immediately placed on a respirator. After a few days, the physician saw that no progress was being made and called in a neurologist. The neurologist diagnosed Mr. A with ALS (Lou Gehrig's Disease) and the family, consisting of mother and daughter Miriam, was told that he would probably be in a vegetative state for the rest of his life. The family, who was moderately religious, called their rabbi and was advised to wait 48 hours before making the decision on whether or not to prolong his life. The very next day Mr. A showed remarkable improvement. He awoke and responded well to all the staff's questions. The family was jubilant. The ICU physicians and the neurologist were apologetic. At this point, however, the ICU physicins wanted to extubate the patient to "see if he could make it on his own". If not, it would confirm that they were only prolonging his death. Miriam, a practicing psychologist from New York City, was extremely upset. She felt that with more time her father would respond to treatment. Her comments reflected upon an insensitive ICU resident who had told her, "why are you punishing yourself? He'll never make it. Mother will probably follow in a couple of months. This is the

usual pattern." Eventually, Mr. A slowly improved and was sent from the ICU to the floor. Other problems arose. The speech therapist announced, "Your father has difficulty eating. It must be a gag disorder caused by a lack of oxygen." Another young resident said, "Your father has become psychotic. We are giving him a special medication." Miriam, who was familiar with medications and her father's medical history, pleaded and prevailed not to give Mr. A any such medication. Mr. A slowly improved. Miriam also showed the staff that Mr. A could indeed swallow and that it only appeared that he couldn't swallow because he always ate very slowly. "Rabbi, it was one incident following another. At least if I could have heard just once, *We don't really know your father's problem.* All I felt was arrogance, cruelty and little, if any, genuine concern, only a need to prove themselves right. Sometimes it's the family who knows the patient best." Eventually, Mr. A recovered and, to my knowledge, has been at home for the past two years.

In summary I note that the whole set of events was very unusual for a few reasons. First, the physicians repeatedly made mistakes. The doctor who should have been in control lost the confidence of the family. Secondly, Miriam was a professional who challenged the physicians. Perhaps she intimidated them. She was articulate and carried herself in a very calm and strong manner. Third, the physician did not pick up on the family's Holocaust history. It was not emphasized by the patient or family, but it was important. The physicians gave up too easily. Younger physicians have a tendency to go out on a limb and then have to rationalize their positions. There was insensitivity. Perhaps it had to do with practical considerations like time constraints and

workloads. There was also a lack of any coordination to the communication in what was said, left unsaid and how it was said. The staff did not listen to the family, did not pick up any cues, showed no empathy and did not reassure or support Miriam in any way. Many physicians do not realize that they are the most important social supports to the family. The case of Mr. A is a classic demonstration of how not to communicate to families.

The Family of Mr. B

Mr. B was hospitalized for bone cancer stemming from an advanced stage of lung cancer. He had indicated to the family that he wanted to live as long as possible. His daughter describes his situation. "Father was slipping, unable to make his own health care decisions. The resident called us in to a meeting asking us to approve a DNR order. The family, however, insisted on full resuscitation. Approximately an hour after this confrontation with the resident, Dr. S., the attending doctor, came in and boldly wanted to revive the issue. My mother said to the doctor, *We already went over this. Do we have to do it now?* The doctor was firm. *We have to come to a sensible decision. Your husband really has no chance of survival. Why put him through this ordeal?* My mother took the doctor's hand, *Look, can't you leave us alone for a while? It's a big decision which takes away hope.* The doctor said he would return later, once we had thought it over."

It is often difficult for a doctor to understand dying patients and their families.

Sometimes they are mentally and physically exhausted which may consequently trigger insensitivity. Physicians often want to get things in perspective as soon as possible. They feel overburdened. They had little time to communicate, which made the "timing" of the communication with Mrs. B. inappropriate. When the family initially refused medical advice, the physician became frustrated. This, in turn, angered the family and they demanded a more aggressive treatment. It is also possible that the family needed more time to discuss alternatives so they immediately opted for aggressive treatment to give themselves time to think it over. Once again, I note the lack of skills in communication. Even if physicians anticipate a negative reaction, it will be more beneficial to them and to the family if their approach will permit the family to express their personal emotional responses. It may be that this is a major cause of breakdown in communication. This inadequate attention to what families are experiencing will increase conflict over medical decisions.

The Family of Mrs. C

Mrs. C was a lady of 90 years admitted to hospital with a serious case of pneumonia and congestive heart failure. She had a history of severe COPD (Chronic Obstructive Pulmonary Disease) for which she had oxygen at home. She also had prior episodes of congestive heart failure. I interviewed her sons, both professionals, approximately one month after her death and they were very bitter about the removal of certain medications and nutritional IV which dehydrated their mother. They wrote, in

a sharp letter, to the hospital; one copy was sent to me[1]:

> Notwithstanding the constant attendance by the family during this period, at no time did any doctor talk to us about Mom's critical condition. In fact, they had actually avoided us. We were never even told about Mom's emaciated state at a meeting on Thursday night on January 7th 1999 between 22:30 and 23:00 - just 3.5 hours before our mother died - with Dr. Brown who knew Mrs. C's medical history very well. This is really quite shocking - very callous - attitude not to inform her sons of her very poor health and possible imminent death.

In replying to these charges, the doctor wrote in a letter, addressed to the Director of Professional Services, explaining why the medications and IVs were withdrawn. He also replied to their comments concerning the lack of any meaningful communication.

> I found these comments very surprising and certainly untrue. I would personally round myself on all patients on the ward first thing in the morning. I saw Mrs. C myself daily and discussed her care with the medical residents daily. I had nearly daily lengthy discussions regarding the critical nature of her illness with one of her sons (I don't know whether it was Mr. G or Mr. H) often interfering with my ability to see other patients. I even told him that I didn't think Mrs. C had a good chance of getting through this admission. I believe that Dr. Green also had similar discussions with that same son. Despite these discussions, he refused to accept the severe nature of his mother's illness.
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> In conclusion, I believe that Mrs. C received maximal and appropriate care during her final admission on 7 West. Her sons were informed on numerous occasions regarding the critical nature of their mother's illness and grave prognosis it carried.

Subsequently, I contacted the sons. They were quite upset, simply saying that the doctor was untruthful. "It was a cover-up." The sons planned to continue their complaint.

I was reminded of my interview with Dr. C who said of the doctor-patient-family communication, "The family, including the patient, do not understand what we are talking about. The doctor says I told the patient one thing. The family says the patient

told us differently... Sometimes I draw pictures to explain. Fifty percent understand, fifty percent do not... even with the notes they are handed." Dr. C's comments on communication referred to cases of non-terminal patients and families. I believe that in terminal cases where patients' and families are initially in shock and denial, the physician's concern about the psychological effects of giving bad news would probably make the communication even less clear.[2] The upshot of this case suggests that clarity in communication could be extremely important. We face the older problem of selective listening and selective remembering as patients and families tend to hear what they want to hear and remember what they want to remember, stifling out any report which paints a dismal picture. Perhaps the use of audiotapes, where families can listen to the tapes about the diagnosis and prognosis, would make it more clear in their minds. On the other hand, physicians may be concerned about misdiagnosis and subsequent consequences.

The Family of Mrs. D

Mrs. D was brought into Emergency. She had difficulty breathing. She had chronic heart failure and diabetes. Her husband was ill at home and could not leave the house. A son had died in his thirties. The only support Mrs. D had was from her single daughter, a lady in her forties whom we shall call Ruth and who had virtually slept in the hospital while Mrs. D was hospitalized. We quote from Ruth at length:

> Emergency was excellent. They took her in immediately, brought her to the CCU, stabilized her and then sent her to the Cardiac floor.

> Immediately the doctors and nurses took over and I was left out of the picture. They gave her tests and sometimes she was without food for 48 hours which is unheard of for a diabetic. I couldn't call a meeting. They ignored me. It was as if the hospital was a political institution. Everybody protects one another. You do for me - I do for you. The shifts in nurses make it even more difficult. You talk to one nurse and then another nurse takes over. I would ask, *What were the test results?* I never had a straight answer. Sometimes I was referred to the receptionist (unit agent). Mother was an optimist. When they would ask her how she felt, she would always answer *fine*. They would say, *So why are you here?* This was a most inappropriate comment. She is a human being. Don't I have a right to challenge a decision they make? They patronize when they talk. I tell them, *Your profession is not about making money. It's a helping profession.* They said they are sending the social worker to talk to mother. I asked that she talk to me first. The social worker came in and I asked her for another appointment so that we could spend some time privately. I said to her, *You look like a nice girl. Perhaps we could meet at another time. As you can see, I am giving mother her lunch.* She shot back, *I am not a girl. I am a woman.* Rabbi, with all her training, was this all she could say to me? I called the ombudsman. She answered, *Put it all in writing.* Rabbi, this is supposed to be a Jewish hospital. We are supposed to be caring and proud of our service. St. Mary's is much more caring than we are. Would you believe that they once asked me how productive Mother was before entering the hospital? I ask you, Rabbi, is this a question a caring hospital is concerned with?

Ruth continued with her complaints. She was articulate and angry as I interviewed her. Her mother was here for a few months before she died in her daughter's arms. Ruth was a charmer. She was street-wise, brought up on Ste. Catherine Street and the Main - a tough Montreal area. She spoke like a character out of Damon Runyon, even using four-letter words, "C'mon Rabbi, you weren't born yesterday. I'm not shocking you."

I was called in on the case after a couple of weeks into Mrs. D's hospitalization. I spoke at length to many of the physicians and nurses who thought that Ruth was a nuisance, exaggerating her mother's problems. They claimed to have given her mother

excellent attention and to have spoken with Ruth at length explaining the situation which she could not accept.

No doubt Ruth was extremely attached to her mother. She always said her mother was her best friend. In my conversations during Mother's hospitalization, I did not confront Ruth. I would say, "They have a different version of what happened." She, in turn, would curse them for lying. I did not want to alienate myself from her. She needed friendship and support. She had few friends. I was her confidante. On many occasions she would say, "The doctors and nurses are the goliaths and I am just a little David. It's not fair." In Mrs. D's case I am reminded of Susan Erstling's article which pointedly said that many families carry difficult personal feelings and problems into the crisis situation. Erstling pointed out that sometimes physicians must treat families as well.[3] This certainly was not the case. The physicians were in no mood to treat Ruth and nor was she ready to be treated. I think she suffered deeply from the loss of her brother, never really coming to terms with it. This was a typical case when patient, family and doctors are stereotyped by each other. Communication is very difficult in these situations.

I am still in touch with Ruth. In a recent letter, she wrote of individual corporate agendas. She asked, "How does one get ahead in a corporation? In a hospital, the resident has an agenda. The doctor has a huge ego and his agenda. The institution's agenda is to get larger government grants. What is more important - research or clinical medicine? Hospital ethics is defined by a corporate culture, corporations which lack integrity. As the doctors walked into my mother's room with their white coats, I kept

thinking of Clint Eastwood's line in one of his movies, *Do you feel lucky today?...* Rabbi, my luck ran out."

The Family of Patient E

Mr. E is an 85-year-old Sephardic Jewish patient who was brought into the ICU suffering from a massive cardiovascular stroke, paralyzed on the right side and in a deep coma-state. Prior to the stroke he was treated for hypertension and diabetes. He appeared to be developing renal failure. After eight days in the ICU without improvement, the family was called in and explained that the situation was futile and that it would be advisable to remove the patient from the respirator. The family consisted of his wife and eight children who were extremely upset. There was crying, breast-beating, and restlessness with the family walking in and out of the ICU. I was called in to try to calm them, without success. The patient was moved to a private cubicle in the ICU in order not to disturb other patients and families. The ICU physicians again called asking me to intervene. The family described the communication with the doctors, "At first they were sympathetic, explaining to us what happened to Father. We were told to wait a few days to see if he would improve. They really tried hard, but when they came to tell us to remove the respirator, Rabbi, this is not according to Halacha. We are observant Jews in a Jewish hospital. They should understand us. We told this to the doctor. He doesn't understand. Father was religious his whole life and now at the end of his life they want to murder him." Again, I tried to explain the ICU's position,

adding that the doctors felt it was not fair to take an ICU bed from a patient that could be cured. They wouldn't listen. They called their Sephardic rabbi who was also a family member. We had a meeting in the ICU. The doctor explained his position, "We know you are a loving family, but this love you now have is misplaced. Now is the time to let go so that he does not suffer. There isn't a chance for him to find any quality to his life." The rabbi replied that the Halacha emphasized sanctity of life and that life coming from God had an infinite dimension which must not be taken away. The doctor began to argue that perhaps the infinity will take place after death, but on earth life is finite. The rabbi was upset. He looked at me and said in Hebrew, "The man is a doctor, knows nothing of our religion and Halacha, but he argues. Do I tell him how to be a doctor? He has no right to tell them what our religion is all about." I turned and told the doctor "The rabbi feels very grateful for your opinion, but he disagrees and says that this is the way the family feels."

The rabbi could have continued his argument. He decided to cut it off. The doctor, as far as the family was concerned, was out of his league when he started to argue religion.[4] It was not his domain. This phenomenon of arguing religion is tempting. We all have ideas and thoughts about religion and what changes should take place, but in this case, when a man is about to die, the beliefs which have been incorporated by individuals and families into their personna should be respected. These beliefs become part and parcel of their very existence and *raison d'être*. This could have been a most important moment in the patient's life - the moment of his death - and he has that right to die as he perhaps thought about his whole life. These are values and

beliefs which deal with the very meaning of life. It was, in my opinion, inappropriate for the physician to argue interpretations of faith at this time. What was needed was a sensitivity and understanding towards the family. Like medicine, religion deals with life and death on a spiritual plane and the family's concerns should have not been challenged by the physician at this most sensitive moment.

The Family of Patient F

I met the family of Patient F in Emergency. They were extremely upset. The family had to wait for three or four hours in the waiting room before the patient was seen. The Emergency was jammed. The patient had a history of diabetes and kidney problems. Finally, he was brought in and hospitalized in Emergency, but respiratory complications began to set in. His status worsened and he was sent upstairs into a medical unit and put on a respirator. The family blamed the hospital for his problems, especially the "heartless doctors in Emergency". They threatened a lawsuit. I was called in to smooth the situation. The family, consisting of a wife and son, said that they were going to get to the bottom of this to really see who was responsible. "The doctors are in cahoots. They protect each other. They are not interested in the patients or their families." The family was adamant, inconsolable. I talked to the doctor in charge and we agreed on calling in a specialist of their choice from another hospital. The family consented and got in touch with a doctor from the Royal Victoria Hospital who came to visit the patient and family the next day. After meeting with the specialist from the

Royal Victoria Hospital, they became much calmer and accepting of the situation. They explained: "The doctor was a *Mensch*. He sat down with us and explained the situation from beginning to end, showing us how the disease progressed and the present situation. We felt he wasn't taking sides. He just showed a genuine interest in us. We offered him an envelope for his trouble, but he refused. Now that's a *Mensch*!"

There is a calming effect in using a second opinion in certain cases. When the family is in doubt about what happened, feeling under pressure and having a distrust for the attending staff, it may serve a purpose to call for an independent view. The problem often is that the physicians are communicating information while the families are expessing feelings. Thus, each side is not really listening to each other. Both sides, in arguing their case, want to have the last word. The use of a second opinion opens the door to physicians who listen to both sides and could be more empathetic to the family. Of course, the process has to be in the open and all parties need to be aware of what is going on. Unfortunately, this is not always the case. Physicians may feel undermined when second opinions are suggested. They naturally resent it for it challenges their competence. But the situation demanded it. The staff was glad to cede to the family's wishes. The visiting physician was in a mediating position and he played his role exceedingly well.

The Family of Mr. G

Mr. G is a 60-year-old immigrant from Israel working as a plumber, who has

been told by his physician that his congestive heart failure has deteriorated and he should get things in order just in case. The family was shocked at the doctor's arrogance in not having informed them first. The patient was emotionally paralyzed. In fact, he had told the doctor, "Please do not tell me anything. Tell it to my family. All I ask is to be made comfortable and that you do what is best for me." The family was extremely upset and shocked at the doctor's arrogance in having told the patient and not informing them first. When they met with the doctor, they explained their feelings. The doctor argued that his first allegiance was to the patient and that he always advises the patient first. "I didn't tell him anything that should have upset him. I am usually quite gentle and in my estimation, he probably knows more than you think. From our research, your father has probably no more than six months to live." The family told me, "We were shocked. What kind of doctor would do or say such a thing?" I replied, "Look, I know the doctor. He is good and he cares. His style is to tell the patient first. He meant well. It is his way. Many doctors have the same approach. Patients are different too. Some, like your father, take it badly, but many others accept it. In fact, it would be surprising to me if your father didn't realize the gravity of the situation." The family was shocked at my reasoning.

There are two major factors of which many physicians are unaware. First, there are cultural factors in communication. In countries bordering the Mediterranean, including Spain, Israel, Greece, Italy, North Africa, and the Mid-East and even in South America, physicians are expected to speak to the family first, before they speak to the patient. It is the same in China and Japan. Patients are seldom told that they have a

terminal disease. They may have been told, "You have a small tumour, but we'll fix it up." This is a normal approach to the patient. Even when the family is told the truth, words are usually couched in an encouraging tone not to upset them. Sometimes, if the family is vulnerable and sensitive, even the best efforts to communicate are bound to upset them. Second, when the physician said, "The patient has six months to live," he was speculating. Research that tells us that fifty percent of patients die in six months also tells us that fifty percent live longer or shorter. Further, what do statistics about a group of patients mean to a single individual who wants to live and enjoy his family? For that patient it is all or none. Frank and honest discussion which emphasizes elements of hope is the key to communication. I recall in my family, my father-in-law was given six months to live. He lived for seven years. This is not an isolated story. Only if the patient is ready to listen should statistics be applied with clarification of the possibilities including treatment plans. These are delicate moments. Some ingredients of hope should always be present.[5]

The Family of Mr. H

Mr. H, a prominent Montreal businessman, was brought in to the hospital by air ambulance and was transferred to our CCU (Coronary Care Unit) after suffering a second heart attack in two months. The second attack occurred in Florida and was complicated by a cardiac arrest. Mr. H never woke up subsequent to this arrest. This very religious family consisted of mother, son and daughter who were with the patient

night and day for his twelve day stay. During this period, the physician had many conversations with the family and especially the son, whom we shall call Joe - who was designated as the spokesperson for the family. At first things went well, but when Mr. H. did not wake up after a week, both doctor and family decided to call in second and third opinions which corroborated the cardiologist's diagnosis of irreversible brain damage. At this point the cardiologist suggested removing the respirator and "Let nature take its course." The family was upset. I was called in to "speak to the doctor" about the importance of the sanctity of life and that out of respect for the patient, the physicians should keep him on the respirator until his time came. The doctors were unhappy. Words were exchanged. The son called the doctor a "liar" to his face. The doctor remained calm. Other cardiologists became involved and tried to explain the futility of the situation to the family to no avail. The treating cardiologist told me, "Rabbi, if religious factors were not an issue, we would have withdrawn the respirator six days ago. I tried so hard for the family. I spoke for hours at length. I invested so much time and effort in this case. There was no appreciation." The family in turn said, "He misled us. He knew we were religious and would never accept his suggestion to remove the ventilator."

Mr. H died about two weeks after entering into the hospital. I interviewed the family about a month after his death. I was told, "Rabbi, it's your fault. You have to teach the doctors that it's a Jewish hospital. It should be hospital policy. It's a terrible hospital. They hide things from you. They are two-faced. They say one thing and do another." I later met the cardiologist and he said, "They never left the denial stage.

They thought things would turn around to the end. They expected a miracle. It just didn't happen and we are to blame."

It has now been a year since Mr. H died and the family now seems to have accepted Mr. H's fate. We subsequently had a civil and candid conversation. "Rabbi, we are believing Jews. His time came. It was *Bashert* (pre-ordained). They really tried hard, but it wasn't meant to be."

In retrospect, there may be a strong psychological dimension to communicating, especially at the bedside and even after the patient has died. There may be a vast difference between the psychological and practical dimension in family-physician communication. The former deals in theory with what is going on in the patient and family and has very few suggestions in the practical sense. The physician in the ICU, cardiologist in the CCU, or oncologist is not really equipped to deal with any of the psychological aspects but can only offer his empathy by listening and giving of his time. This leads us to a question. Does communication always have to have a happy ending? I wonder if this is not a normal phenomenon of communication in end of life situations. The psycho-social dimensions are so vast. Perhaps there is a sense of normalcy in that strained, difficult and even poor communication can only be expected under certain circumstances. Maybe the denials, pressures and avoidance of honest communication are also within a normal range and very little can be done about them.

The Family of Mr. I

Mrs. I was a 75-year-old lady who was being treated for an acute myelogeneous leukemia. Her family consisted of two sons, both in their early fifties. Palliative care was suggested to the sons. They agreed. They were extremely devoted. They took turns at the bedside almost fifteen hours a day. "Mom was the greatest. She brought us up alone. Our father died when we were kids. She taught us the value of a dollar. She took each dollar and made certain she bought two dollars worth of merchandise. Not a nickel was wasted. All we have told her is that she had a small tumour which we are treating. The treatment has temporarily been stopped. We avoided the word *cancer.*" The sons had given instructions to the doctor not to say anything to Mother about the cancer. The doctor agreed, saying "For what purpose? What are we gaining by telling her? She seems so frightened by all of this and the fact that you are there day and night to be at her side is the most comforting component."

This approach is still very common among many Jewish patients, families and doctors. The patient is not usually told that his illness is terminal. Families which consist of younger and more educated children are becoming slightly more truthful in their approach. They would still not be direct to the patient, but may continuously ask the patient if she has any questions.

There may be a few reasons why this approach is taken. First, as above, the doctor believes the family knows the patient best. He goes along with the family. Second, we would speculate that the physician is not in accord with the family but only

accedes to their wishes because he/she does not want to create any conflict which is not likely to be helpful for those involved. Third, the family and the doctor are afraid of upsetting the patient because of their own anxieties. A social and communicative distance is maintained that creates a detriment to any meaningful conversation. There is an unspoken wish to avoid any emotional-laden confrontation. Even when Mother does ask questions, the family shuts the door. "Don't talk like that. Be positive. You are going to get better." Finally, physicians and families are sometimes not aware of communicative skills. They know the two extremes - either you tell or you hide the truth. They don't have the "know-how" or skills to listen to a patient, to respond to his cues, or to know how much to tell or how swiftly or slowly to proceed. They do not know how to reassure the patient. They have little capacity for empathy and seem to be in a hurry to leave the bedside even as they come into a room.

The Family of Mr. J

A similar episode was described to me by the family of Mr. J, an 80-year-old gentleman admitted to Emergency having difficulty breathing. His sons who had brought him in said that he had been suffering from congestive heart failure for many years and they had told his physician that his father did not want to talk about death. This family request, as often happens, was not charted. On an evening shift, a young resident came in and sat down and gently told him that he was very ill and in all probability he would not leave the hospital. He suggested that there should be a DNR order and that Mr. J.

should prepare himself because his time was coming. Mr. J was very upset and agitated. In the morning, he told the story to his son, who, in turn, searched for the resident. He found him and asked him, "Who gave you the permission to tell my father his prognosis?" The resident replied that if there was a request not to tell him, this was most unusual and that it would be better if Mr. J knew the truth. The son immediately went to the physician in charge and told him the story. The physician, in turn, went to the father and gave him a much more hopeful prognosis practically assuring him that he would go home.

The problem, in this case, is that great damage was already done. It was most difficult to rectify. First, in this case as in many others, discussing DNR orders can cut off communication. This is a great danger in discussing DNR in general. Second, the words of the young resident will always haunt the patient. Third, what good will be accomplished by telling a hurtful truth to a patient who openly said, "I do not want to know." A question, however, does arise. Was the second physician trying to help the patient or was he trying to calm the agitated family? I believe it had to do with trust. The patient trusted the second physician who quieted the family.

The Family of Patient K

Mr. K was a 70-year-old Jewish Sephardic gentleman who came into the ICU with cancer in the lungs, compounded by asthma and chronic obstructive pulmonary disease all attributed to a 50-year-old habit of smoking at least two packs a day. His

family included a son and two daughters who insisted on full aggressive treatment. After two weeks in the ICU, the physicians recommended that he be transferred to a regular floor, arguing that the ICU is only for patients who have a reasonable chance of survival. Feelings of bitterness developed between the ICU team and the family. The family felt alienated. The physicians saw the family as completely unreasonable. After a while, there was hardly any communication between both parties. At one point, a physician piped in that the ICU cost $2000 a day. "Would the family be willing to pay for it, and, if not, do the physicians not have the responsibility to society to keep health care costs down so the others who can be saved should have the chance to be treated?" This last question raised the ire of the family. "Since when do financial considerations decide whether or not to treat a patient?" Religious issues were brought into the conflict. A battle ensued. There was one point of agreement. They agreed that representatives of the Ethics Committee meet with the family in the presence of the doctors. This was to take place in a few days since the hospital ethicist was not available. In the meantime the situation became very, very tense. Harsh words were spoken. I was called from the ICU to meet with the family. I realized that there was very little chance for any meaningful communication at that time. Interestingly, the doctors in the ICU and the nurses were somewhat at odds. The doctors argued that optimally and theoretically money should not be discussed, but we live in the "real world" and government pressures remind us of our obligation to others. Some of the nurses, on the other hand, quietly told me that the families had a point and that this issue of money should not have been brought up. I left the ICU and an hour later I had a call from an excited doctor.

"Rabbi, it was a miracle. Mr. K just died. Our problem is solved. It would have been hell in here."

In retrospect, the battle dissolved. Nothing was really solved. In the end we could only reflect on the role of the Ethics Committee. What would they have said? We can imagine that the positions were somewhat polarized; the family claiming that any decision should not be based on costs while the doctors would defend the position of the ICU. This is the trap many Ethics Committees fall into, the temptation to arbitrate the decision of who is right and who is wrong. This should not, at this time, be the major concern. The Ethics sub-committee meeting the family should at first listen to the family. Why do they want such aggressive treatment under such painful circumstances? Is it out of love, a promise made to the patient or the patient's expressed opinion? Is there full agreement in the family? Are there other motives or alternative treatments? Perhaps the family needed time. We become so engrossed, bogged down with the ethical issues, we forget to address the major family concerns and begin the process of communication which would alleviate the situation.

The Family of Mrs. L

This episode occurred on a Sunday afternoon in January 1998. Mrs. L, a seventy-five-year-old woman, was dying of metastatic cancer which originated in the uterus and spread quickly throughout her body. She was a Holocaust survivor, brave, full of life, and very close to her family, consisting of a married son and daughter who

were with her almost constantly. On this Sunday afternoon the patient was doing poorly, complaining of severe pain. The family was told that the morphine dose, scheduled for every four hours, had already been given. The family pleaded that she was going to die anyway. "Please give it to her as she needs. We want her to die in dignity." The nurses refused. They argued that there had to be a change in the order and that they could not do it alone. The resident was called on the phone and he, too, refused to change the order. The son spoke to him and pleaded again, "Look, who's in pain? Is it the patient or the doctor?" The resident replied, "It's against any protocol and I will not do it. That dose of morphine every four hours is more than enough." This was at about 2 PM. The family called me in at about 2:30 PM to see if I could help. We called the resident, but received no reply. We called again at 3:30 PM, and again, no reply. I personally called the resident at about 4 o'clock and received no reply. In the meantime, Mrs. L. was groaning, vomiting and soiled her diaper. At 4:30 PM morphine was administered. We called again for the resident. There was no reply. The family and even the nurse were quite upset. At 5 o'clock we tried again to no avail - not even a return phone call. At 5:30 PM Mrs. L died. The family was angry. "Mother died in pain. There was no compassion." Finally, the resident arrived at about 5:45 PM explaining that he was just extremely busy covering for another resident and Emergency was jammed. The family refused to talk to him.

Such cases of abandonment, fortunately, do not happen very often. But on a wintery Sunday afternoon with half staff working, it can happen. If Mrs. L had not died, it would have been recorded as a terrible experience, but excuseable. We could say,

"We were short-staffed and we just could not get to the patient." It was not only their mother's pain that bothered the family. It was the lack of dignity, her suffering. It was a public indignity. Mrs. L was retching and puking, smelling up the room. The nurses cleaned up. The family was just overwhelmed by the situation and the perceived lack of interest in their mother.[6]

What we have learned from this case is that there are different types and grades of abandonment. Most of us have experienced cases where physicians show up many hours after the original call. We do not call this abandonment. Medical care is a scarce resource. There is, however, abandonment by the physician, which often happens if the patient is deemed incurable and has not been transferred to Palliative Care. A second type is more embarrassing. This occurs when the family abandons the patient. Finally, as in our case, there is an abandonment which appears ruthlessly intensive. For the family it's as if the physician is saying, "Why should I bother? The situation is futile!" This is how the family perceived it. They could have forgiven the physician if he had at least showed up. He might have passed by and explained that it was against the law to give further doses of morphine and that his absence was due to a shortage of doctors in Emergency. His complete absence when Mother was in such pain and suffering and all this indignity heaped upon her was inexcuseable.

The Family of Mr. M

This is the case of Mr. M, a 70-year-old Jewish Sephardic patient who was

operated for a bowel obstruction. A severe sepsis followed the operation. And after about four weeks the patient became comatose and was deemed to be dying within hours by the staff. The family was called in. They were eight children, sons and daughters-in-laws, who were divided on the issue of bringing in the *Chevra Kadisha* (holy community of gentlemen to say the final prayers). The staff remained very respectful. They moved the patient out of the main ICU unit into a cubicle so that other patients would not be disturbed. The group who did not want the *Chevra Kadisha* were waiting for a miracle. They refused to give up. The second group of children were more realistic. The physician and nurses in their deliberations with the family explained that they did everything possible and that now he was in the hands of God. These words, of course, upset the group which was hoping for a miracle. They felt the ICU was giving up and not trying to cure the patient. They had no complaints about the care, but only about the attitude of the ICU doctors who did not believe in miracles.

The problem of "waiting for a miracle" is almost generic, especially if the patient is considered young. It is no wonder that families seek that miracle, especially in the ICU where high tech and human engineering prevail to save the lives of many patients. The terms "miracle drug" and "miracle technology" are used as a marketing device on TV and newspapers by hospitals and pharmaceutical research companies who often claim success in complex medical issues with announcements of miracle cures. But the hope for miracles usually evokes a negative response from the staff. The families are described as in denial, irrational, avoiding reality. When this communication involving "miracles" results in negative responses by the caregiver, the relationship with the family

usually deteriorates.

In an article by C.H. Rushton and Reverend Kathleen Russell, the authors explain the dynamics of acute miracles in four ways. First, "there is the deep and painful process of acceptance. Acceptance means more than medical realities. It means losing a child or person who is loved and has been a source of joy to the family. To accept that reality is to proceed along a path of grief. A path a family or parent already walks; yet may resist walking deeper."[7]

Second, dealing with the reality of losing a loved one can mean a threat and challenge in how we deal with God. "How could God let this happen to my child? Is this the God I thought I have?"[8] Third, clinging to the presence of a miracle is considered being faithful to God. "Faced with a situation in which they see themselves as being forced to choose between the human interpretation ("we've done all we can; maybe it's time to let Ronnie go") and the spiritual ("God is in charge; He could still work a miracle for Ronnie"), parents choose the latter as a way of being faithful to God and to their child.[9]

Fourth, the concept of suffering for the faithful is different than for the medical team. "What physicians and nurses may see as meaningless prolongation of physical and emotional pain, some parents may see as a time of profound meaning and purpose in which God is at work. Some faith traditions see suffering as a time to get closer to God and to be perfected in faith. Suffering may also be seen as the means through which God's power is demonstrated or God's truth is revealed and it is not within the realm of mortals to interfere. In these instances, what is redemptive for the family may be very

disturbing or absurd to the team."[10]

The authors offer some strategies for caregivers, and conclude that it is difficult for caregivers to understand the meaning of miracles in the context of treatments for critically ill or terminally ill children. "Conflicts of this type will not be resolved easily. A genuine commitment of family-centred care requires that health care professionals create an environment where diversity of viewpoints can be respected and includes appropriate support systems and resources."[11]

The Family of Mr. N

Mr. N was admitted with carcinoma between the esophagus and stomach. He was operated upon and told by the surgeon, together with family, that the operation was not completely successful. There was a certain area that was not completely cleared of the cancer cells. It was now a matter of time. The family was caring and devoted and the room seemed relatively happy in the sense that there were no feelings of gloom and doom. I interviewed the family. "The doctor was kind. His first words were, I'll never forget. *He's not dead yet! Let's give him a sense of control. Don't treat him like a child. Let's give him dignity.*"

"Rabbi, these words have been translated into action. We listened to him. We haven't abandonned him. We keep our word. We are on time every day to see him. He knows we are there. Sometimes it's tough when he cries to himself, but he knows we care. We try to give him dignity."

Dignity is important. There may be dignity in dying a painless and quiet death. The major dignity however, for the patient, is when the family and team is there during these difficult times. The success in this story was, of course, dependent on a family which absorbed and integrated the simple and direct communication from the physician. I cannot help but ponder about other families who do not have the capacities of Family N. Perhaps they haven't got the time to give to the patient because of their own immediate family needs and commitments. Perhaps they are poorly educated or emotionally unable to give of themselves as Family N.

I recall a similar case our family had with my father in March 1988 at the Jewish. Dad was a tough successful action-oriented business man, hardly ever taking a vacation. He was placed on our Geriatric floor at the age of 94 with multiple serious prostate and kidney problems. The team called the family to a meeting and we agreed on DNR orders, but not the palliative care they had suggested. Dad was not for palliative care. He was a born fighter and would never give up. In fact, when he first came into the hospital we had to hide his shoes so that he wouldn't wander out of the hospital. We hired sitters almost around the clock. The family which included four sons and a daughter, their wives, husbands and children, were there most of the time during the day.

Dad refused to talk of his illness. He was in official denial, but we could see that privately he prayed more often. Once, while I was about to enter the room, I heard him talking to himself. I soon realized that he was talking out loud to God in Yiddish. "What do you want from me? I have so many *mitzvot* (good deeds) to do. I've got to get out of here so that I may serve You better!" And here he switched to English, and

he said, "The ball is in Your court!" I did not go into the room. I had some tears to shed.

The doctors said, "Give him dignity to the end." We gave him dignity. This is what he wanted. Once I came into the room with my tie purposely crooked. He gave me hell. "What kind of a rabbi are you to look like that? You work in a hospital and you have a responsible job. You have to learn to be neat!" My brothers would come in with some ridiculous tales. "Dad we've got a problem. Maybe you can help." My children would come in and ask him about translations of a words in Yiddish or Hebrew. We tried to give him dignity so that he would know we still needed him.

It was sad in the end. Dad died fighting and swearing at the nurses who tied his hands to the bed so that he would not take out his IVs and bring harm to himself. It was hard to watch. He died like he lived - fighting to the end.

But what about the thousands of LTC (long-term care) patients who cannot afford sitters? What about those children who live out of town or alienated from family? We may also wonder about those who have Alzheimer's, where dignity is hard to find. Finally, what about those who feel abandoned and are left to die?

The Family and the Last Three Questions

I now turn to my last three questions concerning the rights of the physicians as opposed to those of the family and patient when they clash in a medically futile situation. Whereas the physician's concern was mainly with inappropriate family intervention in

a strictly medical domain and the problem of distributive justice, virtually all the families interviewed claim that all final decisions should be left to the family. To some, the questions were ludicrous, astounding. "What do you mean to say? Do doctors have the right to pull the plug according their own decisions and wishes? How can you ask such a question?" Others were understanding. "The family knows best what to do." Still others want to invoke religion and culture, claiming that it was a Jewish hospital and that we should never entertain such thoughts. "It's plain murder." I tried to explain that it wasn't a simple decision. We have to consider the physicians who feel that we have to take account of bed shortages and that they are not practicing honest medicine when families dictate what should be done. My words usually fell on deaf ears.

The above family arguments span the four different categories of replies, as mentioned earlier.[12] It made no difference if families totally agreed to terminate life-sustaining measures towards their family members or not. All categories agreed that in cases of conflict between staff and families, the family should have the last say.

To solve this dilemma of physician/family conflict, better communication would be the first priority. I will be discussing methodology in communication in Chapter VII. However, these questions and family responses illustrate the depth of the problem. Most court cases in medical ethics can be attributed to a breakdown in communication. First, I offer suggestions and ideas for better communication, but there is no guarantee that they will work. Second, we could try to avoid clashes by improving protocols which would clearly define the rights of physicians and patients. However, these protocols, as clear as they may be, are just the beginning of a process of better communication. This

was emphasized in the recent Herman Krausz case, when the coroner, in her findings, pointed out that if Mr. Krausz had insisted on continuing his intubation, the doctors would have had to listen to him. But in the same decision, the coroner suggested the use of better communicative techniques to solve these confrontational issues.

One further point. When I originally put the question, "Tell me your story", to the family, my objective was to engage the family in order to have their input flow from their feelings. Since the examples given were those from families who had their differences with physicians, I opened up a spectrum of disappointment, disagreement and even anger by allowing them to express and even ventilate their feelings towards the medical staff and hospital. But I learned something else. Through permitting the family to tell their stories, I learned important things about the patients and families that the physicians were not aware of. Some families were Holocaust survivors, some full of guilt, others believed in alternative medicine and still others really did not understand the illness. "We knew the cancer was serious, but Rabbi, we've heard that people could live for years under these conditions." When I went to the homes or businesses for interviews, I saw the affluence, poverty and, in all cases, anger towards the medical profession in general. I saw families who showed me a multitude of pictures expressing their loneliness and dependency on the loved one who had just passed away. I met elderly widows and survivors who were ill themselves. Generally, physicians are unaware of the whole situation.

William J. Donnelly touches upon the subject. Donnelly is concerned with the patient's medical record which may be voluminous but tells us little about the patient.

He states:

> Medical students and physicians will construct more balanced accounts of human illness once they envision these accounts as *story* - a form of narrative that traditionally expresses objective experiences as well as objective events. One can effectively begin the process of transforming medical chronicles into stories simply by asking patients what they know and how they feel about their situation and by documenting the response, using some of the patient's words in the history of present illness. These actions will identify and preserve important information, facilitate empathy in all caregivers who hear or read the history and signal to everyone the physician's serious interest in patients as persons. Getting the voice of the patient into the history of present illness will not only help to write the medical record, but also help to right the relationship of physician and patient.[13]

I, too, in my research on families, have emphasized the narrative. It is the story that gives the fuller view. I might argue that families may be wrong in their assessment of the situation and of their opinions of the doctor. These stories, however, give the larger understanding of their beliefs and concerns of what is happening to the patient and to them. It gives a signal how to approach and communicate to the families. It teaches that there is another side to the medical model which only stresses physical interests. If we listen to families, we may learn of their fears, hopes and how the patient and family can cope with the illness. Thus, I find myself not only addressing the final three questions, but listening to the family's story which tells what went wrong from their view and how they saw the situation.

Family A

Mrs. A was paralyzed seeing her husband in his condition. The family

spokesperson was her daughter, Miriam, a psychologist, who commuted every weekend from New York. "I can understand that unfortunate incidents and mistakes can happen in any hospital. My father's case is not unique. Symptoms can be confusing. But I felt a lack of compassion. Perhaps it's because he speaks only Yiddish and there was difficulty in communicating. However, it goes deeper. They wrote him off. From the time he came to the hospital until he left a few months later, he was misdiagnosed with illnesses and diseases he never had. It has to do with looking at an aged person and deciding that he has no quality of life. What do they know about quality of life? They never went through the Holocaust. What do they know of my father's likes or dislikes? Do they know about his love for his wife? Are they trained in quality of life issues? How can one person decide for another person if life is worth it? Dad would have been dead if not for my intervention. It's family who knows what's best for the patient. Fortunately, I was here to save his life for a while. This proves that families should have the last say."

Perhaps Miriam was unfair in her assessment of the physicians. In fact, the physicians did not "write Mr. A off". They only decided that medical intervention was inappropriate. The point is, however, Miriam thought "they wrote him off". They didn't care. They had no interest. This is how Miriam saw the events. Again, I note the importance of communication as an exchange between parties. The doctors fed information to Miriam but they did not address Miriam's feelings. The tone of communication, as experienced by Miriam, was sterile, without showing any genuine concern. The result was that "they wrote my father off".

Family B

I interviewed Family B again at their home. They had kind words for the doctor and hospital. "Of course, the family should have the last say. They are the true patient advocates. They have a moral responsibility to the patient. If we, the family, will not express ourselves, who can we rely upon? Our loved ones will then be in the hands of strangers. If we do not agree with the physicians, but in the end allow them to do what they think is right, then we are not a family. Someone has to stand up. In our case, we agreed with the doctor in the end. We had the final say and they respected it."

Family C

Family C also argued for family rights in making any final decisions. My questions troubled them. "Doctors don't understand families. They focus on the patient. They only see the patient from a medical view. They don't see the patient in the context of the family. They see the patient from the charts. But behind the charts is a person with a history, a life. Mother was the cornerstone of the family. Does the doctor know this? Does he care? There is an element of *chutzpah* (arrogance) for you to ask these questions. We owe everything we have to our mother who brought us up. And it's not because we owe it to her. It's because we loved her. We tried to give *nachas* (pleasure) to our parents and they gave us *nachas* in return. Can a doctor understand the Jewish flavour of *nachas*? It's not a technical term. It's a loving term."

In Mrs. C's case, we see the response of many Jewish families, especially those who speak Yiddish at home. The translation of *nachas* is "pleasure", but it goes much deeper. It represents "pride". Children try to be a pride to their parents so that their parents can tell their families that they have *nachas* from the children. If parents do not have *nachas* the child is perceived as a failure. The sons of Mrs. C would have seen themselves as failures if they did not protect their mother.

Family D

As we recall, Ruth, the daughter of Mrs. D, was uncontrollably embittered at our hospital and staff. Her mother's death was the hospital's fault. In the end she said, "Everyone was against me. Rabbi, it has to do with attitudes. They made up their mind and they had the final say. It's not fair. If, as you say, the medical profession can argue for unilateral rights, then it shuts down communication."

Unfortunately, it was Ruth who was the major victim. She could not come to terms with her mother's death. According to the physician, her mother died without pain and, when she died, part of Ruth went with her. According to Ruth, Mother died in pain and suffering. "Mother still lives in my heart." It's close to two years since Mother died and her death always enters into our conversation.

Family E

This case is probably the most difficult to define in any area in which we could accommodate doctors and families. The rabbi quoted his version of the Halacha and the family accepted his decision. The Halacha, like most law, is not black and white, nor dogmatic, especially in end of life issues. Further, with the new technologies, a vast body of halachic literature has begun to take shape. It is extremely complicated. Issues such as brain death, organ transplants, invitro fertilization, and genetic engineering need to be answered by an halacha which is just beginning to be aware of these complicated issues. End of life halachic concepts are also very new. These include, by today's standards which change so rapidly, issues of *goses* (definition of a dying person), *traifa* (definitions of defective body organs), and *chayai sha* (definitions of prolonging life or death). These issues are difficult in themselves since each case is different, depending on the capacities and strengths of each patient. Devising any sweeping halacha would be wrong and is indeed very delicate and complicated.

Nevertheless, the family was adamant with regard to their religious rights. They quoted Bleich's old argument, "The doctors are there to cure. If they cannot do it, then the religious leaders must make the decisions. Doctors don't understand how important religion is to the family. They have little respect for religion. More respect is given to minorities from other cultures. In fact, the hospital would boast of how it would protect other cultures, but when it comes to patients of their own faith, Jewish physicians will argue with the family. Children who are ill also get a better break. Is an older man, a

highly respected and loved father, different than a child?" And then the family quoted an old argument, "What if the state wanted to force an abortion on a fifteen year-old girl from a Catholic family? We don't believe any Catholic hospital would allow it. So why should our Jewish hospital disregard our faith when the family insists on respecting it?"

I think their point could be problematic. As one doctor pointed out, "Rabbi, if we keep all the patients who want full resuscitation, for whatever reasons, attached to ventilators, we will not have enough room in the ICU. We will have to build special rooms - and when they are filled, what do we do?" Nevertheless, there is a large body of literature which advocates family rights in religious issues.[14] [15]

Family F

Family F was the family who expressed their anger and blame upon the "heartless" doctors in Emergency after their father had respiratory problems in Emergency and was sent up to the ICU. When I asked about the family versus physician rights in cases of futility, they shot back, "What kind of question is that? Is the physician God? Who knows the patient best? It just goes to show you what's happening in our medical system. The doctors want life and death in their hands." When I tried to explain the physician's position and responsibilities, the family fumed. "Their responsibility is to save the patient. Doctors are here to heal, not to kill. Listen Rabbi, it's coming to a point when there has to be advocacy groups for older patients. They have it for kids. Why not older people who can't fend for themselves? It's the only

way."

It seemed to me that Family F was not open to any dialogue. Perhaps it's their Eastern European background and Holocaust experience. Perhaps I could have called the doctor from the Royal Vic to interview the family with me, but then he, too, would have lost all credibility.

Family G

I interviewed Family G approximately a month after Mr. G died. The family was still in notable grief, appalled at the doctor's behaviour. They could not forgive him for telling the patient the truth. "In Israel, this would never have happened. He took away father's hope. Father was a timid, frightened man." I did not argue, so when I asked them who should have the last word - the doctor or family, they replied, "Are you asking the family to leave it to the doctor? It's a loaded question, but the doctor has a responsibility to ask the family. Each family is different. Each patient is different. Some families will say to let my father die and not suffer, others will say his time will come when God takes him. This is the Jewish way. We are not religious, but this is part of our culture. We are fighters, dreamers and not easily persuaded. It's in our nature."

Family H

The family of Mr. H, like the family of Mr. E, was guided by the Halacha. The doctor respected the family's wishes, but the family still felt that they were misled. Perhaps the family was disappointed because the doctor, quite suddenly, changed the prognosis. Feelings of mistrust entered the picture. I interviewed Joe at his place of business. "The doctor feels that if you have no purpose to life, then it's not worth it. Better to take the patient off the respirator. He doesn't understand that sanctity of life is life itself, even if there is no meaning. If life had to have a purpose, then the doctor is right, but then there should be no difference between active or passive euthanasia. This is what the Germans believed, that there was no purpose to a Jew's life and, therefore, they could practice eugenics upon them."

We had a long session. It was, for me, an enlightening conversation. Perhaps this is why many Jewish people are so sensitive to any form of euthanasia. This, too, may be part of the philosophy of the Right to Life Movement. Life, by itself, has an intrinsic value, an element of sanctity, and must not be extinguished.

Involved as I was in this case, from its early beginnings, I think the family, notwithstanding the halachic issues or mistrust of the doctor, had an abiding hope for a miracle to happen. They weren't prepared for death. Death was the enemy, and it is not only individual families who fear death. The doctors and all medical institutions whose aim it is to save life, see death as the enemy. I see this especially in the role of the Department of Palliative Care, which is almost separate from the rest of our hospital.

Doctors avoid palliative care. It represents a failure to the profession. Some doctors call the Palliative Care Team "the Death Squad". It's hard to communicate the concept of palliative care to other departments like Cardiology or Surgery. There will often be consultations between Cardiology and Surgery on whether a patient can be operated upon, but rarely will you see anyone talk to Surgery or Cardiology about palliative care or end of life issues. It's just not brought up. Palliative care does have a connection to Oncology. This is because cancer is often terminal and concepts of end of life and issues of caring are intrinsic to Oncology. If the patient is not known to Palliative Care, Oncology knows that it is available for any assistance it may need. This is not of any great interest to other departments.

This argument of caring can be extended towards those like Family H who claim that doctors are there to cure and that their role as physicians ends when they can't cure. Physicians, however, are there to care as well. We do see this in Palliative Care, but, unfortunately, it is not as visible in the rest of the hospital. When the doctors suggested removing the respirator from Mr. H, he thought it was an act of caring. Not so with Joe. He interpreted it as murder. These two completely opposite views may only prove the need for good communication.

Family I

Mrs. I's family was extremely protective. This is part of Jewish culture. They didn't want to take away hope of, at least temporary, recovery. The doctor was in full

accord.

There are different elements of hope. Hope can be relative to change, adaptable to situations which allow for a lesser hope or more hope as the patient slips and regains their strength. We may know that we are dying, but we can hope to make it to a wedding, graduation or bar mitzvah. We can also hope to die without pain, or to anticipate a long-awaited visit from a family member. These are realistic hopes. There are also unrealistic hopes when patients hope to leave the hospital well enough to be able to continue their work. These hopes can be either disappointing in the end or carried forward to the very end. It's as if the patient is in complete denial, fighting and hoping when there is no such reasonable hope. As mentioned above, there is a natural denial of death. Accepting death is certainly not easy. There are always elements of ambivalence and there are cultures and faiths which encourage patients to battle until the very end of life. The Jewish faith, with its emphasis on the sanctity of life, is often seen as one such faith. We may also wonder how the families perceive this concept of hope. First, lack of hope threatens the personhood of the patient. Take away hope and the person is no longer what he was. Second, hope is not a cure, but it can be a clinical tool. Hope can give the patient a sustaining power, motivation, physical and psychological strength. Finally, hope is considered vital to a body as it is to the mind and the spirituality of the patient. Take hope away and the patient gives up - physically and mentally. Patients often go into a shell, turning away from the family not because they do not love their families, but because there is very little hope and see nothing in the future.

Family J

The case of Mr. J is similar to that of Mr. I, both families insisted that the patient be protected. In Mr. J's case, the patient expressed a desire not to be told, but the resident followed the book and not Mr. J's wishes. He sincerely believed that patients must know the full truth. On the other hand, the staff physicians agreed with the family. The family and doctor did not want Mr. J to suffer needlessly.

There are basic differences between suffering and pain. Pain can be managed - it can be treated by a pill, a drug. It can be out of control, but we can find ways to ease the pain. Suffering is psychological, spiritual and existential. Suffering has to be managed by patients themselves. We try to intervene spiritually, looking for untapped resources. Guilt is minimized and we show the patient that we care. Thus, we try to help the patient ease his/her suffering. However, when a patient has told the staff not to advise him or tell him the truth, telling the patient will only reinforce his fears and cause suffering. It is also as if the resident interfered with the rights of the patients and families when they most needed support of these rights.

In answer to my questions, the family only said, "If families are not consulted, this is what happens. Families should have the final say. It's amazing, Rabbi, but doctors should learn about different cultures. This is the bottom line. He did not understand us."

Family K

Family K was adamant about the rights of families. "We see life not only as a treasured human possession; life also is a duty. We had a duty to do the best we could for our parents. If we would have listened to the doctors, we would have abandoned and betrayed him. The doctors have their ideas. We have ours. Money should have not entered the decision. This is an ethical issue, not a financial one."

The family, in my view, has merit to their argument. If we argue from a financial view, the problem of our aging society remains in jeopardy. The elderly, by virtue of being old, deserve dignity and comfort. If we only look at the economics of old age security, retirement pensions, costs of medicare and expectations that our younger society, at their expense, is responsible to the older one, then we neglect our ethical responsibilities to our aged.

But it's not so simple. There is also merit to economic considerations as well. Mr. K was a heavy smoker for fifty years. He had to take some responsibility. Further, just because we label certain issues as financial does not mean that they are automatically not ethical. Imagine this scenario: Mr. A, seriously ill, has a private room by default. When he was brought up from Emergency, there were no beds available in public or semi-private wards, so he was given a private room. Mr. B is brought up the next day with a minor problem of cellulitis. He signs the form to pay for a private room. Mr. A is then wheeled into a public room so that Mr. B can have his privacy that he paid for. Is this ethical? It's done every day in hospitals all over the world. We suggest a second

scenario. Mr. K, who may be a prominent and wealthy person, is in Emergency. Emergency suggests the ICU, but the ICU is jammed. Mr. K is refused entry. The family is told, "Find another hospital". The family refuses. They come up to the ICU to speak to the doctor in charge. They tell the doctor, "We'll pay, whatever it is, but, please, we want to take care of him." The physician in charge listens to them and takes them into the main ICU unit. "All right, you tell me which patient to move out of here so that we can make room for Father." Of course, the family gets the message. I have seen this happen.

This is not to say that financial considerations do not bend the system. Occasionally, they do play a role somewhere down the line. Perhaps if you are a member of the board, a prominent politician, or a large donor to the hospital, certain minor operations may be moved in order to accomodate you. These things happen. But in general terms, distributive justice is a major component of ethics and is respected by all departments and the hospital in general.

Family L

I contacted the family about a month after the funeral. Considering their previous anger and frustration, they seemed calm. They had written a letter to the hospital's patient representative asking for an inquiry into Mother's death. They received an affirmative answer and apology for their experience. "It's too late for Mother, but we do not want it to happen to other patients."

It seems to me that in hospital, controlling symptoms such as incontinence is not a major medical priority. Pain control is most important. Although palliative care physicians have special expertise in pain and symptom control, other physicians will have only a general knowledge about controlling pain and even less on the control of other symptoms. Perhaps the physicians are not aware of the feelings of patients about their lack of dignity and the shame and public embarrassement which families feel for their loved ones.

An emotional pain is personally associated with symptom control. Even the well elderly are embarrassed by having to wear diapers even though they are well disguised beneath the user's undergarments. Further, even as we consider physical pain, perhaps the hospital's response time to a patient's pain should be researched in the same way ambulances are timed to reach their patients. I'm not certain this is possible in our hospital given its many different departments. The concept, however, may be a tool which could arouse the staff to answer a patient's call more quickly.

Family M

The family was divided. The physicians tried to appeal to both factions. It was essentially a family problem and the physicians handled it very well. They appealed to both sides.

Theologically, miracles sometimes happen, not always. They happen when something extra-ordinary occurs. They cannot be arranged, controlled or caused to

happen. Part of the family believed that the ICU could bring on this miracle.

Not to believe in miracles or to disregard the importance of Halacha is a withdrawal of faith. The physicians, in their ethical decisions, have more room to manoeuvre than the family. There is a sense of elasticity and tolerance in secular ethics. We usually find two or three sides to every issue. In religious ethics, issues are more concrete. What does religion, God's word, say? We are reluctant to leave life and death issues to the whims of Mother Nature.

In Judaism, the principle of sanctity of life says that man was made in the Image of God. The corollary is that the value of life is infinite and that every part of life is infinite. God gives life, and only He can take life. This is a family in which religion is very important. In hospitals, the view is that science must be the deciding factor. Some families are reluctant to allow this to happen indiscriminantly. They see miracles daily which scientists see as part of nature. Second, even the scientists admit to the odd case which has stumped them. There are cases which scientists describe as miraculous. The family has heard of such cases and attach their hopes towards their loved ones hoping for the same miracle to occur again.

Assessing the Family Interviews

I have thus far commented on each of the family interviews. I will now turn to summarizing these comments, pointing to the salient areas which define the family's position. Once again, I re-iterate that I am only emphasizing the family's views. While

I often comment on these issues, my major purpose is not to pass judgment, only to present them as the family and physicians see them.

In Chapter V, I summarized the Lindemann stars and some Jewish family values which can be found within the framework of each story. Although the Lindemann stars shine throughout my stories, I will only concentrate on an analysis of the Jewish family values which permeate each story. My interviews and interests were with Jewish families and how they responded to our questions. For referral purposes, I list and enumerate the values:

1. Sanctity of Life
2. Valuing Life which I called Fear of Death.
3. Honouring Parents
4. Being a Success attributed to the high-achieving standard.
5. Being a *Mensch* (*Menschlichkeit*)
6. Doing the Right Thing because of guilt feelings.

In the next section, I will analyze the interviews in light of my questions and formulate some hypotheses and compare them to the physicians' responses.

In the case of Family A, the psychologist daughter, Miriam, expressed her concern that the physicians and nurses were labelling the patient as a very ill geriatric gentleman who had no quality of life. It was as if Mr. A had reached a certain plateau, a physical number in which he is now regarded as "excess baggage". The fact of his not being able to communicate in English or French was another barrier.

In terms of the family values, I note how the value of honouring parents and

doing the right thing by them was most important for Miriam. She flew in from New York every weekend to be with her parents. There was a strong sense of duty to be at their side. She was a child of Holocaust survivors and she had to assure them that everything would be done to save Father's life. Of course the principle of sanctity of life was very important; however, I felt that the dedication to her parents as an only daughter was the major factor in her efforts.

Family B saw the physician trying to finalize life and death decisions though manipulating the family, intimidating them to respond quickly as the physician advised. Unfortunately, the family stiffened. They would not fit into the physician's mold. The family claimed to know the patient better. Further, there are different levels of dialogue, depending on the intellectual and emotional capacities of the family. In this case, the physicians were not tuned into the family. They were in no mood to listen, only to dictate terms. The major family values I found were the value of life itself and that one had to be a *mensch*. The family knew of the strong feelings Mr. B had towards prolonging life and abiding by his wishes was their major concern. The family had to live with these values. The doctors were not aware of their feelings since there was no dialogue.

Family C brought further insight towards understanding communication patterns. Notwithstanding the sons' ability to focus on what the doctors told them, we see how parents can be powerful forces in the lives of children - even those who were grown professionals. It was as if Mother was supposed to live forever. Further, the sons were high achievers. They couldn't interpret the doctor's words except according to their own

understanding of the disease and what they wanted to have in the outcome. They took the role of the *menschen*. They had to prove that they controlled the situation.

A few months after Mrs. D died, Ruth came to my office carrying an article printed in *The Gazette* of May 8th, 1997 regarding Dr. Nancy Morrison who was arrested in Halifax, Nova Scotia on suspicion of mercy-killing.[16] After Dr. Morrison was taken into custody, a stress management team was sent to provide the hospital staff with emotional support. Ruth pointed this out to me and felt that she, too, was a major victim in her mother's death. She asked, "What about my having access to a stress management team?" I had nothing to answer. Ruth, indeed, needed emotional support. We didn't give it to her.

In retrospect, Ruth's major fear was losing Mother. Mother was her best friend. They were a "team". She was devastated in the end, blaming all those surrounding her. Everyone was protecting their jobs, untruthful and uncaring. It was not a matter of which value was more or less important. In her love for her mother, all were important and in the end Ruth believed she was the only *mensch*.

In the case of Family E, it was difficult to argue religious issues. If a family approaches a rabbi with a halachic question, the rabbi deals with the question. The question may be, "What do we do in this futile situation? Are we allowed to lower the respirator or to stop feeding this PVS patient?" The rabbi has to define the futility in each situation. He looks at pain and suffering and weighs the chances for recovery. He then opines if the patient should be fed, or operated upon. He takes into account the physical and emotional strengths and, often, the wishes of each patient. There are,

however, families and their rabbis who perceive the situation as black or white. For them, lowering the respirator, not feeding a patient or not administering treatment is tantamount to murder. I recall a religious family whose father was dying. The physician in charge refused to insert any feeding tubes arguing that it would be a futile gesture. The children, who were two medical doctors, insisted that the tube be inserted. The DPS (Director of Professional Services) was called in. He decided in accordance with the family wishes. There was no use arguing with the family. For them, it was a black or white issue. I handed them a copy of a protocol used by many Orthodox patients and families which explain halachic guidelines in these issues.[17] It did not change their mind one iota.

Religious issues are the most difficult to resolve. It is difficult to ask a devout person to give up his/her belief in a God-given law. The value and sanctity of life and honouring parent's wishes were paramount. The only way to convince this family that the reasoning of sanctity of live and honouring parents could be misplaced was to find a rabbi whom they respected to tell them that there are other ways to deal with the issue. I didn't think the family would ever change their mind. In the end, they heard and saw what they wanted to hear and see. Perhaps another way to resolve the issue is to give them more time. Unfortunately the ICU did not have the time. For many religious families, time would not have made a difference.

As we recall, Family F reinforced the belief in the use of second opinions. It was the second opinion which brought a sense of calm to the family and physician. However, it does not always work, as shown in the nationally-known case of Mr. Andrew Sawatski

of Manitoba in November 1998.[18] Mr. Sawatski, a heart and stroke patient, was also diagnosed with Parkinson's and dementia. He was placed on a PVS and DNR list. This was opposed by his wife, Mrs. Helene Sawatski, who contested that the DNR order was inappropriate. She claimed that her husband wanted to live and the hospital's decision was based on limited resources versus patient's rights. A second opinion was requested and Dr. Allan Simpson and two of his colleagues came to visit Mr. Sawatski. They attested to the fact that he was not in a vegetative state as described by hospital authorities. They argued, "great pressures are placed upon the aged and the ill to give up. Even when they suggested DNR to the family, you have to find out if it also means no antibiotics." A research bioethicist, Tom Koch, phoned from Hawaii, "physicians are not good judges of what is an acceptable lifestyle. It's highly personal. Physicians are not trained in quality of life. Physicians who usually make these decisions are young. How do they know if it's going to be worth it? Justice Sam Filer from the Ontario Court of Justice has been afflicted with ALS. His wife said in public that doctors told him if it gets worse and he needs to be ventilated, not to do it. But he and his wife said they would do it." There has to be a meeting of minds between the physicians and families. Fortunately, in our case of Family F, there was a meeting of minds. The problem arises, however, in cases similar to the Sawatskis where there is no meeting of minds and a second opinion only adds fuel to the family's case against the hospital. In our case, the problem was a faulty perception by the family that Emergency had given up too quickly on Mr. F. Perhaps it was the manner in which the case was presented to the family or the family's belief that more should have been done (a high achievement

family). Finally, it was the *menschlichkeit* of the consultant physician that saved the day.

The physicians in the Families G, I and J cases took it upon themselves to advise the patient of the seriousness of the illness without consulting the family and even over-riding the patient's expressed wishes in certain instances. This was a value judgment. Even though treatment was not indicated, it was not only a medical question - it was a moral one too. The physician's decision was to go directly to the patient, ignoring the family. This approach fed into the conflict. The physician decided to exert his authority without consulting the family. We may find variations on this theme, but this may be the crux of the battle between physicians and families. When families and physicians make unilateral decisions, it is because they do not have the capacities to share their values with each other before reaching a decision.

The family values expressed in these cases primarily involved protecting the patient from facing his terminal illness and doing the right thing - which was associated with being a *mensch*. The family's indignation against the staff stemmed from a sense of responsibility on the family's part. It was expected of them. To respond otherwise would have been morally wrong.

Returning to the family of Mr. H, we again witness the powerful role of religion in the futility debate. The problem is, in most of these cases we are forced to interpret the religious issues as the family sees them. In this case, the family consulted an authority who was very strict in his interpretation of the law. Nevertheless, in the end, the family found consolation in the *Baschert* (pre-ordained) concept. This same concept, if realized earlier, would have saved the family, hospital and physicians much grief. The

communication needed time and because of the shortage of funds in the CCU (Coronary Care Unit), the physicians couldn't wait much longer. This time factor contributed to the anxiety and pressures of both family and physicians.

Family I seemed to be dictating the terms of Mrs. I's death. Mrs. I was protective of her sons when she ran the household. Now it was the sons' turn to be protective of her. On the other hand, Mrs. I, who was a dominant family force, had lost the ability to express herself. The family had taken upon themselves to make all decisions. This was their understanding of Mother's dignity, protecting her from any decision process. This, too, is a strong cultural Jewish response. The sons are also both tall, outspoken and imposing figures. Perhaps the doctors didn't want to create an argument with them as well. Again, the protectiveness on the parts of the sons is a syndrome often encountered in Jewish culture as a repayment of a mother's protectiveness of the children. In other words, we owe our parents and if we don't live up to expectations, we have failed them. Thus, we have the traits of overprotectiveness, responsibility to our parents and the guilt with which the children would have had to contend with if they failed Mother.

There is another factor to consider which I have previously touched upon. It is quite probable that these sons would not have wanted to be protected under the same circumstances. Would it have been appropriate to ask the sons, "What would you have wanted for yourself under these circumstances? Wouldn't you want to know the truth?" This, however, may not be a fair question. We do not know how we would respond in a terminal condition. It is one thing to answer when we are physically well but we may

produce a completely different answer when we are ill and frightened. This is most notable in the reluctance of people to write a living will. They do not know how they will feel when they become terminally ill. Deciding for family members is more complex than deciding for strangers or even for oneself. Oft times we feel that we owe a debt to the ill family member and conceding death is not easy. Schneiderman and Jecker write, "Friends and family members may feel an unlimited obligation to provide nurturing, personal time, life-savings, and even life itself... What may happen in such situations is that the person one loves has become such a central part of one's life that the loss of that person is tantamount to losing one's self. Perhaps, underneath, Mr. Wanglie's demand for continued treatment was the question he could not face: if I am no longer her husband, who am I?"[19] In Mrs. I's case, underneath the son's protective approach was a similar question, "If we are no longer sons, then what are we?"

In Mr. J's case, the physician knowingly rejected the patient's request to have no knowledge of his diagnosis. He thought it would be in the best interest of the patient to tell him the full truth. This case emphasizes and makes vivid the argument that decisions involving futility can be value-laden and not neutral. For the family and patient, his decision was devastating.

In examining Mr. J's case, I wish to emphasize that even a neutral approach to a medical decision can devastate a family. Perhaps we must be concerned about the perception of the recipient in such a decision. How does the patient feel about the decision to be told the full truth? How did the family understand the resident physician's decision to tell all? The physician may argue, "I am only telling Mr. J. how it is - for

his sake. There were no other values to espouse in my decision. It is strictly medical." Nevertheless, to the patient and family, the doctor may have medical expertise, but a complete lack of vision of how the patient and family would respond to his neutral position. The physician did not understand the high values placed in protecting the patient and that was the way to honour the parents.

In a presentation given by Dr. Michelle Chaban titled, "Support of Families in Patient Palliative Care", we learn that the new trend in palliative care is not to be blunt in telling the truth to the patient and family. Dr. Chaban used the term, "we have stopped shooting the truth with both barrels blazing". She explained palliative care as a process. It begins with risk-modifying care, followed by curative care and palliative care including symptom and pain control and supportive care. Only at the very end is there care intended to plan for and manage death, and even then, it is done in a very delicate and supportive manner.[20]

The major value that Family K. embraced was that they believed they were the *menschen* and not the physicians. They had very high expectations from the staff.

There are a few lessons we can gather from the case of Mrs. L. I have discussed abandonment in general. I now try to analyze it in terms of the family. I have mentioned that abandonment is often part and parcel of the response to futility. The physician raises his/her hands and makes three statements. "There is nothing more we can do. At this point we will try to keep Mother comfortable. She is in God's hands." The family focuses on the second statement. "At least Mother will not suffer. She will be made comfortable. They will not abandon her." However, it is not simple. Mother

is given morphine every four hours. The physician tries to find a balance which will make her comfortable and yet not affect her respiratory capacities. As the situation worsens and Mother remains in pain, the doctor's hands are tied. Some physicians will accede to the family or patient's wishes and administer it every three hours. But for some patients the pain threshold may demand further doses and this is refused.

At this point, the family becomes upset. They know about hospital protocol but Mother may be moaning or suffering. What can they do? First, they have lost control of the situation. They see no semblance of dignity for Mother. In this case, it was not only the pain but the symptoms which were not controlled. The family says, "We don't expect Mother to survive, but does she have to die in pain without her dignity?" The family begins to lose trust in the whole system. They continuously call the doctor. Their eyes are fixed on the elevator door. The doctor doesn't show. Perhaps he knows what they are going to ask. He can't do it. He avoids the family. They see it as abandonment. They call the rabbi. It's not a matter of any spiritual support. They are focused on some medical intervention at least for symptom control. Time becomes an overwhelming factor. Every minute is like an hour. Before the crisis, the family tried to maximize time with the patient. Mother was a Holocaust survivor. The children knew of her fears and of their role and which they now felt they were not fulfilling. The resident was not aware of Mrs. L's past.

The bottom line may be that we aren't prepared for death. We don't know how to handle it. Death is the enemy. This may also be an underlying fear of the physician. "What do I tell the family? How do I handle the situation?" I say to myself, "Why

doesn't the doctor show up? Let's give the patient and family some dignity at least at the end of life. This is our last chance. I hope we don't miss it." It wasn't to be.

A Further Analysis of the Family Interviews

Up to this point I have primarily assessed and analyzed the family responses from the view of Jewish family values as enumerated on page 325. I will now further analyze the responses offering a general overview while endeavouring to understand some of the dynamics of the patients' and families' feelings at this most difficult time in their lives. Thus, it is just a continuation of our previous section.

As I return to analyze my interviews, I am reminded, once again, that the vast majority of the families were generally satisfied with the physician's approach to end of life issues. There were some complaints about certain physicians, their attitudes, ability to communicate and interpretation of futility. Generally, the family accepted the physician's advice. My interviews, as presented, were with families who were confrontational, dissatisfied with the physician's communicatative approach and their positions in defining the futility of the situation. They were adamant concerning their right to demand treatment which was considered medically inappropriate by the physicians. We must also remember that these families were not necessarily difficult, dysfunctional or argumentative. They were average people who were forced into a position of negotiating the terms and events surrounding the death of a loved family member. Should doctors resuscitate an ailing and aged parent, operate upon a beloved

husband or wife who has little chance of survival, continue respiratory ventilation or inducing artificial feeding for a relative who is terminally ill? The doctor says we are prolonging death. The family says we are prolonging life. These are difficult questions. Everyone in this negotiating process is uncomfortable. This is perhaps the way it should be.

In response to my second question, "When they told you the bad news, did they tell the family first or the patient?", almost all the families believed that they were told first. This is in agreement with the results from the physicians. Most of the physicians spoke first to the family and then to the patient. This may be a Jewish cultural response or, as we have mentioned earlier, the physicians find it easier to talk to the family especially when there is bad news. Further, the family is in a position to help the physician approach the patient. It is important to note, however, that my analysis does not include out-patients who privately visit their doctor's office.[21] My questions were asked in a hospital setting where families and patients are directly involved with the attending staff.

From a cultural position, I have also constantly noted that Jewish families tend to be overprotective of their parents. Concepts of duty, honouring parents and the elderly will motivate families to form a protective shell around their parents and loved ones. Thus, our previous conception of a sacred, private, confidential, covenantal relationship between physician and patient is changing towards a physician-family and patient relationship. My conclusion, therefore, would state, "In the hospital setting, with the Jewish patients, physicians will first tell the bad news to the family and then to the

patient."

I turn now to the final three questions, including: 3) Do you believe doctors have the right to end treatment in a medically futile situation, or can the family insist on further aggressive treatment? 4) If the doctor disagreed with you, how would you respond? 5) In cases of an impasse, who should have the final say?

The families were virtually unanimous in their response to these questions. The families believe that they know the patient best and that they should have the final say. This answer did not come from any philosophical, religious, ethical or well thought out position. It was a spontaneous response to a question which was considered incredible. Who would want to let others decide when and how their loved ones should die? It was not to say that the families claim that physicians have no rights or that the cost of resources should not be considered. But these issues are to be discussed over coffee, at a public meeting, or at ethics rounds - not when it involves their own family member. It is difficult - almost impossible - to be objective under such stress. I recall Rabbi M. Tendler who was invited to speak at a chaplaincy conference in our hospital on halachic issues of transplantation. One of the local rabbis in the audience was giving Rabbi Tendler a difficult time, even lecturing him on his lenient position when the halacha would say otherwise. While the rabbi's lecture was proceeding, Rabbi Tendler whispered to me, "Myer, if it was his own father who needed the transplant, we would be hearing a different lecture." This, the concept of a personal family response, also reminded me of Lindemanns' ethics of intimacy in which families are considered vulnerable to those whom they love. It is this intimacy which is the glue which binds

families together. Thus, in consideration of the family's responses to the last three questions, I conclude that "Jewish families claim to know the patient best and have the exclusive right to decide whether or not to terminate treatment for their dying family member".

This conclusion may be very important to consider as we enter this new millennium. In a research project conducted by David A. Asch et al, 879 ICU physicians were asked about their practices in withholding life-sustaining treatment on the basis of futility. Twenty-five percent of the physicians withheld treatment without the consent of family or patient, 14% without the knowledge of the patient or family, 3% despite the objections of the patient or family. Twenty-three percent of the respondent physicians were on the ethics committees of their respective hospitals. Four percent were from Jewish hospitals.[22] In many local hospital critical intervention policies, the withdrawal of life-sustaining apparatus may be permitted with the signature of three physicians. I would suspect that ICUs in Jewish hospitals in the larger population centres would have a great reluctance to withdraw life support without the consent of family or patient. The above results show that paternalism still reigns supreme in many ICU settings. In fact, some physicians on medical and geriatric floors will issue DNR orders without the knowledge of families provided that two physicians sign the order. The presumption is that families are asked at first, but if the physicians disagree with the family, they can override the family wishes.

A third conclusion from my interviews would say that "Jewish religious families would be reluctant to accept any suggestions which would end aggressive treatment for

the terminally ill." I noted this reluctance especially in the cases of Families A, E, H and M whose family members were religiously inclined. A study by Moshe Sonnenblick et al in Jerusalem, Israel corroborates the conclusion. They interviewed 108 children of 48 terminally ill patients and found "a significant majority requested the continuation of fluid, nutrition and medication (78%, 66%, 73% respectively)... factors that significantly affected the offsprings' decisions were the degree of religious observance and close relationship. Approximately 50% of offspring believed that they knew their parent's wishes, but most of them did not comply with their parent's wishes." They conclude, "basic life-sustaining measures are requested for the terminally ill patients by most of the offspring. A significant minority even requested aggressive life-sustaining measures. The degree of religiosity and closeness of relationship influenced offspring's request most strongly."[23]

The factors contributing to this phenomenon are first, religious families believe that the sanctity of life is the primary value in illness and death. This is an intrinsic value not based on any measurement of quality of life or even the personal wishes of the patient. Human beings do not possess absolute title to their bodies. This belongs to his/her Creator.

A corollary belief is that extending life is an expression of sanctity of life. Thus, if we can extend the life of a patient, even though we realize that it is only a temporary measure, we are obligated to provide this to the patient, providing he/she is not suffering.[24] The Sonnenblick et al study was surprising in light of my research. The high percentages of offspring that wanted life-sustaining measures was astonishing to me.

Another associated belief which reinforces the sanctity of life attitude is the belief in the sanctity of the body. Thus, even after the demise of the patient, the Halacha does not permit any general autopsies. The body must be buried as soon as possible after death. In Halachic literature it is called *Kavod Hamet* (to honour the dead) which is an extremely important mitzvah. Even in the cases where autopsy is mandated under certain circumstances, a rabbi must attend the autopsy to make certain the body is covered as if it were an operation and to be certain that all organs and blood are returned to the body for burial. Thus Jewish people, religious or not, shy away from autopsies.

The mitzvah of honouring parents is another reason for religious families not to give up easily. Some may feel they owe it to their parents; others feel it is a duty while still others primarily base it on love and affection. This is not to suggest that it is only a Jewish phenomenon, but Jewish families are especially known to be masters at instilling guilt between generations. This is invariably noticeable in children who live out of town. They always initially insist on aggressive treatment for their terminally ill parents. Associated with guilt is the high achievement syndrome. I noticed this in the families of Patients D, H, I, K and L who had very high expectations of physicians and themselves as family members. Some of these families are children of Holocaust survivors, some were from small families while others were from immigrant parentage who pushed the children to do well. It is possible that some social workers may describe these families as dysfunctional. They often might claim that children who are tied to parents' wishes do not have the freedom to find their own identity. These children should not feel obligated to take care of their parents to the extent that they are

overprotective of them. Many Jewish families will not accept this theory. On the contrary, children are proud to be overprotective. Many of them expressed how they suffered while their lives are put on hold while their parents were in the hospital. They would stay and, oft times, sleep in the same room on a cot supplied by the hospital. If the patient died, families would ask the rabbi to mention how devoted they were. This is standard practice for a eulogy. Children are to be devoted, loving and, above all, supportive and caring.

Conclusion

I might generally conclude that Jewish cultural factors and values, including the stress on sanctity of life, prolonging life (fear of death), duty to parents, overprotectiveness, high achievement standards and issues of guilt feelings are the major factors in family responses to end of life decisions. However, I would not attempt to suggest that any one of the above values is in any way more prevalent than others. First, there is an overlap among the values and there could be, within each case, many different values, including those of the Nelsons, which have influenced the family's appoach to facing death. Second, it is difficult to measure with any certainty which values are more important in each family. Finally, my only purpose was to bring these values as important factors to consider as we face Jewish families who wish to understand their responses so that we may find a guidepost in order to reach them and communicate with them in these most difficult moments.

Further, because of these Jewish cultural factors, my previous conclusion which fitted physicians' responses into three different periods of time is not applicable to our families. As we recall, physicians responded to my interviews according to the changes in our health care system. Before the nineteen seventies, physicians were recognized and rated the most important persons in hospital care. The result was a sense of paternalism. Medical ethics was left to the physicians since doctors knew what was best for all. With the advent of medicare in the early seventies, patients were considered the highest priority. Doctors began to feel the loss of power. Ethical issues concerning patient care came front and centre to the public. Hospitals and physicians were forced to respond. Since the late eighties until the present, government and hospital administrations are controlling hospitals, physicians and patients. Financial considerations have become a leading factor in all major medical decision processes either overtly or from behind the scenes. Thus, medical ethics is struggling to maintain a moral position in a society which has placed balanced budgets as its major priority.

I hypothesized that those three periods produced different responses to my questions from the physicians. The first period, when the older physicians were in the limelight, gave them the natural right to make all decisions in futility. In the second period when patients were the primary subjects in the system, the principles of informed consent, autonomy and patients' rights became the most important ethical concerns. The present period which targets balanced hospital budgets finds younger doctors scrambling to fulfill an administrative model in which patients can be discharged from the hospital as soon as possible for home care. These pressures are extremely difficult for patients,

families and physicians to handle. Finding a balance between the welfare of patients, medical costs and physicians' concerns over their treatment of patients in the area of futility has brought forth many ethical issues which have to resolved.

Family attitudes towards futility have not seemed to conform to changes in any of the above periods. As I have noted, many Jewish families are still adament in making certain everything possible is done to save their parents' lives. Even family fragmentation in our very mobile society does not seem to affect the families' attitudes towards their terminally ill parents. On the contrary. It sometimes hardens their position in their demand for aggressive treatment. Further studies along these lines in our aging society may be appropriate.

Returning to Ruth of Family D, she considered herself very supportive and caring. Her mother probably thought the same. Ruth was there constantly. She was Mother's strength and Mother missed her when she wasn't there. For some families there is a fine line between dysfunction and support. Perhaps Erstling would have referred to Ruth as dysfunctional. But Mother and Ruth may have provided strength for each other. Ruth had a style of coping and communicating which was unique. Perhaps we have to learn how to accept different communicative approaches. Ruth felt that there was no alternative. This is the way both mother and daughter were coping. Intervening in the process might have been more disastrous. Was Ruth dysfunctional in the process? Perhaps sometimes, but in the end she added years to Mother's life.

If I agreed with Schneiderman and Jecker, I could also conclude that "Many families are personally and emotionally involved and incapable of making rational

decisions". Although this may be true in some cases, most of the families would disagree. They argue, "We know the patient better. We know what he/she would have wanted."

In my experience, however, there are major problems with these last two statements. They sound logical and fair but they may not be right. First, in their overprotectedness, most family members haven't had an open discussion with the patient. Second, patients change their minds. They fluctuate in their modes of thinking. Their moods change. It's hard to know what patients really want. There may be further complications. Thomasma, in a response to Sonnenblick et al's research, was "astounded" to learn that approximately fifty percent of the families knew their parent's wishes and yet over half of these went against the wishes of the parents. Thomasma suggests that the offspring may have felt the patients were depressed when they made their choice and now they wanted to "discount the previously expressed wish of the parent and come down on the side of prolonging life"[25]. And although I think that the children in Sonnenblick's study who went against their parents' wishes and wanted to prolong life probably did so from a religious point of view, Thomasma opens up the argument that children read into parents' wishes and really do not know what the parents want.

Let us look at a fairly typical scenario. The competent younger patient whom we shall call Debbie is terminally ill from cancer. She feels life is coming to a close. She finds it hard to accept. Two options are open. She could fight or be at peace. Both are normal reactions. Her mind fluctuates. If she decides to give up the fight, her family

and relatives will usually not accept it. First they will encourage her and try to give her hope. The natural instinct points to life. Second, she may have been an important person, a pillar of strength in the family circle. The family may have to find a new psychosocial equilibrium of coping if she dies. Debbie is bright. She picks up the cue and plays along with the family until she slips into a coma. At this point, Debbie is considered incompetent. The family is asked to make a decision. Do we resuscitate or force feed? The doctors says, "What would Debbie have wanted?" The family is uncertain. They, too, realize that Debbie may have been playing along. The family waffles. They go to the doctor, "What do you think, Doc? Should we resuscitate and feed?" The doctor says, "In my opinion, let her go. Let's not prolong it." The family goes along, or may decide for other reasons to insist on prolonging life. In either case, the family is reading into Debbie's wishes or even going against her wishes.

There is another very common scenario. In this case, a cancer-ridden dying patient, Jack, says to himself - and sometimes to me - "Enough is enough. I am tired. I've had my life and now it's time for me to go to the world beyond." The family, including his wife of fifty years and two daughters who have loved Jack dearly, try to persuade him to eat. Jack refuses. When they come into the room, he turns on his side, his back to his daughters. "Rabbi, what's happening to him? He was never like this." I tried to talk to Jack but received no answer. It's like he's given up, completely uninterested in his family or environment.

This phenomenon puzzled me. Why the sudden distancing from family? What is the patient thinking? Is he angry and with whom? His wife and daughters can't

understand it. Is he angry with God? I ask him, but receive no reply. He turns on his side away from me.

An answer to this puzzle came to me when I read William May's book "The Patient's Ordeal".[26] May writes about illness and the disintegration of the self which is connected to a body image, his family and community and how the body serves as a medium in which the self discloses itself to others. To illustrate his point, May refers to the famous *Dax* case in which Donald Cowart and his father were involved in an explosion and fire which killed his father and severely burned two thirds of his body - including his face, eyes, ears, hands and feet - leaving him charred, severely scorched where just an instant before he was a 27 year-old man who had walked freely. He is described as a recently discharged jet pilot, a veteran of Vietnam who excelled as a golfer, surfer, football player, runner and rodeo cowboy. He remained conscious during the disaster. A gentlemen on the scene recalls Donald Cowart said to him "Go help my father and then ask the farmer for a gun. Don't you see I am a dead man? I can't live."[27] May describes how Donald Cowart eventually changes his name to Dax. Don Cowart was dead. He writes, "despite the ingenuity of reconstructive surgery, he will never be able to write his full name again; he can only manage Dax. But the name change also fits symbolically. He knows that Donald Cowart has, if not biologically, existentially died; he must assume a new identity."[28]

In order to understand May's innovative approach, we quote from him extensively.

> This substantive dispute between the values of life and quality of life quickly leads to a controversy over who should decide. Dax's doctors

> and the medical establishment tend to fight unconditionally for life. Therefore, Dax must contest their right to decide whether he lives or dies. He invokes the principle of autonomy, asserts his right of self-determination, and inveighs against preemptive and paternalistic action of the medical staff.
>
> The Dax case, however, challenges this conventional analysis of the great moral issues in medical ethics. When we see the basic issue in medical catastrophe as a conflict between the values of life and quality of life, we make a series of false assumptions. First, we think of life as unlinear. We imagine it a straight line that begins with birth and concludes with biological death. The line has a beginning and an end. All else in between we characterize by the substantive: life. The line changes, of course. The living creature undergoes, through his own making and through fate and fortune, a series of modifications for which we reserve the term "quality of life". Sometimes the line fattens and we think of the subject's quality of life as good; at other times it thins out and we characterize the quality of life as poor. A varying quality of life simply suggests variations in the same substantive - life. It allows for qualifications or modifications, but no more.
>
> The current formulation of the arguments between pro-lifers and pro-quality-of-lifers tends to obscure and distort the plight of Dax and others who have suffered a major illness or trauma. The traumatized person has not experienced his life as a continuous straight line that will eventually end in biological death. He perceives the catastrophe as annihilating. The lifeline has already been broken, whether through a single event, a series of events, or a single event that sets off a series of secondary and devastating consequences, including the ordeal of treatment. The highway accident, the devastating fire, the mental breakdown of a family member, the irreversible, progressive and immobilizing disease, or the nasty divorce; they do not merely qualify life at its edges. They break off the old life.[29]

I have quoted May at length because I feel it fits very well with Jack's scenario. Jack, and many other patients who made the decision to discontinue any efforts to prolong their lives, may be telling us Dax's message, "For all intents and purposes, I am already dead. What do you want from me? My body has left me. I am useless. I don't want visitors. I have nothing to say. I have no quality to my life. I have no life. Just leave me alone." This may be devastating to the family, but if May is right in arguing

that a catastrophe can move a man from life through a kind of death towards a new identity, then Jack is saying, "Forget about the old Jack. He doesn't exist any more. This is a new Jack and I want to die. I have nothing left."

The family continues to question the doctor. "What happened? Why the change?" The doctor says, "Maybe Jack is telling us something". The family suggests "Maybe he's depressed. What about an anti-depressant?" The doctor often answers, "We'll give it a try."

I am not certain that May is completely on the mark. The patient has not died yet and perhaps his older personality has not been severed completely. Perhaps there is a remnant of the old Jack and the newer Jack doesn't want to cope any more. Debbie, who faced the identical illness, was more cooperative. She was communicative, did not want to hurt her family and did not go into a shell. Debbie's personality showed certain strengths whereas Jack folded his cards. It's difficult to analyze.

The upshot of this discussion is precisely to say that it is difficult to enter into a patient's mind and emotions. There are many scenarios and it's difficult to predict how patients respond, how they feel and how they present themselves. Perhaps Debbie and Jack wanted to be at peace and looked forward to another world beyond. On the other hand, maybe the family was right. We had to encourage the patient. There was an obligation to give them hope. After all, there is a natural denial to death. However, perhaps Schneiderman et al are right. Families are emotionally involved and it is difficult for them to make a clear decison. Just maybe, all indecisions and questions regarding Debbie, Jack and countless others are because we haven't been open in

discussion with the patient. For even if the patient fluctuates and expresses indecision, we have an insight into the patient's feelings. We can continue from that point.

I believe that if it were possible for us - which it is not - as healthy individuals to imagine ourselves in a terminally ill position, three major factors might enter our minds. First, we would not want to be in pain or in a suffering position for any length of time. Most of us, I believe, would be concerned with our body image, our minds, and dignity and would not want to linger too long. This would concur with May. Second, and perhaps most important, is that we would not want to burden our families, emotionally, physically, and financially. Third, we may presume that we would want to put our financial situation and some personal matters, which we might have, in good order. Of course, these are things which we think about when we are well, but when we are dying it may be completely different. For those of us who have or have not discussed these issues with our families, what happens when we come into the hospital, or become terminally ill? The families and doctors have to make decisions. May says there are two sets of decisions. The first he calls "quandary" ethics which would say, "We can save the patient's life. Let's go to it." Or, "We cannot save the patient's life. Let him/her go naturally." No doubt, these are major decisions. But then a new set of ethical issues begins. "What shall we do with the patient now that we have saved him/her?" May calls these questions "virtue" ethics, questions where we now have the responsibility, doctor and family, to make certain that the patient receives the best treatment possible.

It is all these issues which confront doctors and families. And so when we say,

"What would the patient have wanted?" or, "What's in the best interest of the patient?" these questions are quite complicated from the family's position. The questions and variables are numerous. The patient can be confused and families quite complicated. The physician, now, wants quick decisions. The answer in most cases, I believe, lies in communication which is the topic of the next chapter and the key to my whole thesis.

Notes

1. The names of the physicians in the following exchange of letters have been changed.

2. There have been many studies on doctor-patient communication and satisfaction. For a comprehensive view, see Lea Baider et al. "The Impact of Perceived Behaviour on Patient-Physician Satisfaction", Communicating with the Cancer Patient: Information and Truth, the Annals of the New York Academy of Sciences, eds. Antonella Surbonne and Matjas Zwitter (The New York Academy of Sciences, 1997), vol. 809: 266-278.

3. Susan Erstling, 393-394.

4. See Appendix D.

5. Communicating with Cancer Patients: Information and Truth Annals of the New York Academy of Sciences (1997), vol. 809. Eds. Antonella Surbonne and Matjes Zwitter. This theme continues throughout the whole book. Different cultures have different attitudes towards communicating with the dying person.

6. Perhaps the family could have claimed negligence on the part of the doctor and hospital. Although deeply embittered, the family did not want to initiate any case against the "Jewish" hospital. Mother would not have wanted it. It would be an insult to the Jewish community.

7. Cindy Hylton Rushton and Reverend Kathleen Russell, "The Language of Miracles: Ethical Challenges", *Journal of Pediatric Nursing* 22, no. 1 (January/February 1996): 65.

8. *Ibid.*, 65.

9. *Ibid.*, 65.

10. *Ibid.*, 65.

11. *Ibid.*, 67.

12. Pps. 275-276.

13. William J. Donnelly, "Righting the Medical Record", *Journal of the American Medical Association* 260, no. 6 (August 12, 1988): 823.

14. Robert D. Orr and Leigh B. Genesen, "Requests for Inappropriate Treatment Based on Religious Beliefs", *Journal of Medical Ethics* 23 (1997): 142-147.

15. John J. Paris and Mark Poorman, "When Religious Beliefs and Medical Judgements Conflict", Medical Futility, eds. Marjorie B. Zucker and Harold D. Zucker (New York: Cambridge University Press), 85-97.

16. Stephen McCloud, "MD Accused of Murder", *The Montreal Gazette*, 8 May 1997, 1.

17. See Appendix E, Abraham Steinberg, "Halachic Guidelines for ICU Patients", (Jerusalem: Share Zedek Medical Center).

18. My description of the Andrew Sawatski case is taken from CBC Radio Cross Country Checkup, November 15, 1998.

19. Nancy S. Jeckerman and Lawrence J. Schneiderman, "When Families Request That Everything Possible Be Done", *Journal of Medicine and Philosophy* 20 (1995): 145-163. The authors were discussing the Helga Wanglie case which we have discussed on our page 62.

20. Michelle Chaban, "Support of Patients and Families in Palliative Care" at a conference in Toronto, Ontario titled "Quality of Care at the End of Life" (June 15, 1999).

21. It is possible that families are advised first, even in these cases - especially in situations where children bring the patient to the doctor and the doctor knows some of the family members.

22. David A. Asch, John Hansen-Flaschen, and Paul N. Lanken, "Decisions to Limit or Continue Life-Sustaining Treatment by Critical Care Physicians in the United States: Conflicts Between Physician Practices and Patient Wishes", *American Journal of Respiratory Critical Care Medicine* 151 (1995): 288-292.

23. Moshe Sonnenblick, Yechiel Friedlander and Abraham Steinberg, "Dissociating Between the Wishes of Terminally Ill Patients and the Decisions of Their Offspring", *Journal of American Geriatrics Society* 41 (1993): 599-604.

24. This is a delicate point because, on the other hand, we are not permitted by the Halacha to prolong death. How do we decide? The families we interviewed believed that we are prolonging life and not prolonging death.

25. David C. Thomasma, "Reflections on the Offspring's Ethical Role in Decision for Incompetent Patients: A Response to Sonnenblick, Freedlander and Steinberg", *Journal of the American Geriatrics Society* 41, no. 6 (June 1993): 684-685.

26. William F. May, The Patient's Ordeal (Bloomington: Indiana University Press, 1991).

27. *Ibid.*, 16.

28. *Ibid.*, 16.

29. *Ibid.*, 21.

CHAPTER VII

A COLLABORATIVE MODEL IN COMMUNICATION

Introduction

In Chapter II I examined four different approaches to resolving the futility debate. I concluded that the best way to resolve the futility issue is to concentrate on good communication. Were we to accept the view of Scheiderman and Jecker, who believe that physicians should have the last word, or that of Lindemann and Veatch who emphasize patient and family rights, we would find ourselves in the unhappy position of forcing an issue which leaves the losing parties extremely dissatisfied. The third alternative advocated by Murphy and Lantos, who are concerned with the lack of financial resources, would force government towards closure of the debate, leaving all parties frustrated. It would mean the end of medical care as we have known it in the past. Medical decisions would no longer be the domain of physicians and patients. Thus, the only acceptable alternative is that of Zawacki and Youngner who argue that communication between all parties must be emphasized so that some form of an agreement may be reached. I have also concluded that it should not be an issue of who is right or wrong in the debate. This approach would be futile in itself for these issues are extremely sensitive, involving life and death and the many variables we have to

consider. It is the process of communication which holds the key to a consensus. How we conduct a communication process which would encourage all parties to explain their positions and listen to others in an atmosphere of civility and reciprocity is a basic goal of my method. Above all, we have to show that we care and allow the various parties to take their time to be able to see each other's point of view and, hopefully, change their positions gracefully. But while Zawacki and Youngner speak in general terms, I will offer a fuller collaborative model of communication which shows how the process can take place.

The first section of this chapter will deal with some of the general problems and impediments which patients, families and physicians face while communicating. I will discuss the issues within the framework of the major players' concern. These include: a) government and hospital; b) the physician; and c) the Jewish family.

The second section will deal with how, why and where problems arise. While there may be different ethical rationales and approaches which examine all the difficulties and frustrations, I will primarily examine the situation by analyzing how families and doctors communicate with each other. It is my belief that good communication may neutralize some of the difficult issues. Through focusing on communication, we can learn the major personal concerns of patients, families and physicians in each situation so that we can work towards seeking mutually satisfying remedies for the concerned parties.

Thirdly, I will discuss what can be done within these communicative exchanges in order to make some improvements. Again, I stress that there is a tendency to

moralize, to place blame on either doctors for seeking to medicalize or control too much, or to blame the families for being uncooperative. In fact, much of my thesis provided evidence to blame the situation on one party or another. At this point, I believe that we could improve the situation by treating it neutrally as a problem in communication and by offering a collaborative model which may, hopefully, facilitate the ability to come to a mutually satisfactory decision. There is one final reminder which I entrust to my readers. I am primarily dealing with families from my research. As noted in the introduction to this thesis, I estimate that only 5% of the hospital family population have had unfortunate experiences with physicians at the end of the patient's life. Because of this clash, physicians were perceived by the families as neglectful and uncaring. This perception is in the very nature of my thesis. And although I, too, have a bias towards patient autonomy and family rights through, perhaps, the nature of my position in Chaplaincy, I do not mean to appear unsympathetic regarding the concerns of our generally excellent physicians.

The Major Players

1. The Hospital and Government

Our first, and probably foremost problem, is the hospital and government emphasis on the administrative model[1] approach to health care. With this model, the purpose of the physician is to treat the disease, nothing else. The goal is to get the

patient out of hospital as soon as possible. It is almost as if the hospital's major concerns are the immediate financial constraints which must be considered in every decision. Thus, the physician is pressured to see the disease from a strict scientific view. While the patient, doctor and family see the disease as personal suffering, physically debilitating and potentially destroying the life of the patient and family, the government cannot become personally involved.

The result is that the whole system breeds a lack of trust and a sense of not really caring. The physicians are overwhelmed with numbers. They haven't the time to listen or converse with patients or families. The family may ask, "Does the doctor really know who my father is? Does he know what he tried to accomplish with his life? He was a fighter all his life. He built himself up from scratch. He built a business and a home. He has fine children whom he is proud of, and now he tells our family that it is in his best interest to give up the ship. Does the doctor know who he really is? Is he/she even interested?"

Another dimension arises in the framework of the administrative model. This model creates an atmosphere which breeds a lack of communication. The pressures of a limited forty-eight hour stay in a crowded hospital Emergency, which encourages sending the patient home, sets a tone which does not allow for meaningful communication. The patient who walks into the Emergency, not having come by ambulance, can have an average three to four hour wait until he/she is seen by the doctor. It's a strange and straining atmosphere. Their personal physician, if they have one, is now geographically and politically distanced from their case. They must rely on

a house staff who changes rotation three times a day. On weekends, sometimes, physicians from other services are on duty. Consulting specialities are also involved. The patient may have a cardiologist, a nephrologist, oncologist, and pulmonary specialist looking after him/her. Because of the character of the system, patients and families are speaking to many different doctors all giving confusing diagnoses. It is no wonder that patients and families are often very confused about what the doctor told them. Pressures in Emergency are overwhelming. The Emergency Department in the Jewish General is known as one of the best in the province. It has been praised over and over again by the government who refers to it as "state of the art". It's the envy of all other hospitals who are forced to keep patients in corridors, and yet, the system is under pressure, bursting at the seams. We have built a magnificent, spacious Emergency area, but if there are no beds upstairs to accept the patients, the pressures become crushing.

I offer a scenario. The doctor wants to admit a patient on a medical floor. He phones Booking (special admitting unit which assigns the rooms). "Sorry Doc, no beds available on 4 West." "Can we book him off service?" "Sorry, we are full right through." "Can he have a place in the short-term stay unit?" "Sorry, that's booked too." "Can we get him into a holding area?" "Sorry, it's full too. Can you hang on till the morning? There are going to be discharges in the morning." The patient is then told he has to stay a second night in Emergency. He is exhausted and says to his wife, "Get me out of here." The wife hangs around trying to get the attention of a doctor or a nurse. She doesn't know what to do. She wants to ask a question. They are so busy. She listens to the conversation between doctors and nurses. "What do we do with the

patient in Bed 8?" "What's the diagnosis in Bed 14?" "The one in 20 - she's quite ill." She thinks to herself, "there has to be a better way. Patients are people - not just numbers. But who can blame the staff. There are so many patients, few doctors and new emergencies every minute. It's a miracle they can just keep up with the situation."

2. *The Physicians*

There are other factors reinforced by the administrative model which directly impinge on the physician's approach towards the patient and family. First is that physician/patient/family communication is not perceived as being conducted on a level playing field. When physicians speak from authority as scientists and professionals, the conversation may lack a sense of respectfulness and reciprocity. Families face physicians who are often concerned with prestige and a knowledge of which the family knows little. While physicians may feel that they are only part of a complex system of medical care and only desire to be helpful, the family sees it differently. They see themselves as vulnerable, almost at the mercy of the physician, who is on the front line of the medical system. The family looks to the physician for a cure, even on a temporary basis, so that the family will continue to function as in the past. For the family, the doctor is in control.[2]

In describing the language used in the administrative model, Smith and Pettigrew[3] divided it into four areas: 1) history taking; 2) doctor's orders; 3) compliance; and 4) informed consent. History taking is when the doctor takes the history

from the patient. Through the physician's way of thinking, the patient is only to be concerned with facts and events, not with feelings and emotions. The patient's medical history is information-oriented and only the doctor knows its meaning.[4] Doctor's orders means that communication is directive, not persuasive. The orders have to be unambiguous and the task is get the information clearly to the patient. The patients will do what they are told. If not, the patients are non-compliant.[5]

A further observation from the above authors claims that informed consent implies that the doctor's job is to inform - the patient's is to consent. Informing does not imply taking over or explaining options. The doctor discloses risks and benefits and the patient either consents or does not.[6] The patient's fears, feelings and images are not part of the process. Should the patient decide not to consent, the treatment cannot go further because the patient is considered to be uncooperative. Failing to consent is like being non-compliant. In fairness to the physicians, however, it must be recognized that it is the same administrative model which has tripled their workload while a common complaint is that they are struggling to make ends meet. Despite these complaints, most physicians see themselves explaining the options, thereby allowing the patient to make an informed decision. Smith and Pettigrew see this as a disclosure. The doctor discloses and the patient does or does not consent.

Jay Katz also presents various models, including the medical model which views the physician as the expert and dominant decision-maker. The goal of informed consent in the medical model is only to disclose enough information to get compliance from the patient. This is the heart and soul of his book titled, The Silent World of the Doctor and

Patient. He writes,

> In what follows here, I wish to convey the stark silence that throughout medical history has been the hallmark of physicians' attitudes towards patients' participation in medical decision making. When I speak of silence, I do not mean to suggest that physicians have not talked to their patients at all. Of course, they have conversed with patients about all kinds of matters, but they have not, except inadvertently, employed words to invite patients' participation in sharing the burden of making joint decisions.[7]

Katz offers an interactive and psychoanalytic model based upon a communicative approach which protects the patient and informed consent. His model is developed on themes which include trust, patient autonomy and acknowledgement of medical uncertainty.

Briefly, Katz argues that although the professional seeks freedom from lay control, the foundation of trust is built upon the belief that "No single right decision exists for how the life of health and illness should be lived."[8] The patient has a duty to reflect and a right to be informed through respectful conversation. Patients do not have to make "sense" to their physicians. Physicians, however, are obligated to try to prevent irrational choices by their duty to converse - even in the face of a waiver by the patient of his right to discuss the illness. As a psychoanalyst, Katz relies heavily on a psychological autonomy which expects the patient to reflect, choose, and act with an awareness of the internal and external influences and reasons they wish to accept. He writes,

> If I am correct, an individual freedom should be equated neither with simply permitting patients to do what they initially desire nor with requiring them simply to make complete sense to their physicians. Instead, and above all, respect for freedom would demand respectful conversation. True freedom entails constant struggle and anguish with

> oneself and with others. This is the lesson of psychoanalysis and its theories about human conduct and interactions.[9]

The last pillar which forms his model is based upon tolerance and admission of uncertainty by the physician. Acknowledging uncertainty forces the physician to practice more carefully in his/her choice of treatment and, secondly, it may lead the patient to decide upon fewer medical interventions, avoid unnecessary surgery, antibiotics and tranquilizers. Physicians have the propensity to solve uncertainty and ambiguity by action rather than inaction. It is not my purpose to expound on Katz's model, but we do see that the present administrative model fosters a paternalism with little regard to patients' and families' feelings.

Another concern about the administrative model is the fear of persuasion and manipulation on the part of the medical team. These are very complicated ethical issues for any communicative approach and especially for a system which advocates the administrative model.[10] When the physician tells the family that a DNR order is appropriate because the chances of survival are so slim, the physician feels he is telling the truth. For him, it is being gently persuasive. If the family finds out that about 10% can survive the CPR, they feel the physician was manipulative. For them, the physician was not completely honest.[11]

If we examine the above disagreement between the physician and family from a communicative level, we note four different issues arising from this communication. First, we are concerned whether the physician's communication was deceptive and distorted. Second, did the physician disclose the full information to the family? Third, was the information intelligently presented to the family so that the family could well

understand the situation? Finally, was it stated in a caring manner? The physician may feel that he/she fulfilled all the criteria. He/she was not trying to be deceptive, he/she fully disclosed the patient's chances for survival and it was intelligently and caringly explained. Thus, the physician believed he/she was completely honest. The family felt different. Because the physician omitted to tell them that there was a 10% survival rate, the physician was deceptive, did not completely disclose the information and therefore the information was not stated intelligently or caringly. For the family, the physician was dishonest.

Another danger presents itself in the incompetent patient. The doctor may believe that "in the best interests of the patient we should discontinue treatment". The families may feel that this is manipulative. "What right do they have to tell me, a family member, what is in the best interests of my father's life? Do they know my father?" The physician may imply that sometimes families cannot be objective; however it is the perception that counts and the family may hear the physician's remarks as bordering on arrogance and manipulation.

Again, from a communicative level, the position of the family may have to do with a) their capacity to listen and understand what the physician had to say; b) how well did the physician explain the situation, and; c) the setting of the conversation in space and time. Was the information given to the family timed to reasonably coincide with the family's readiness to accept the information (not suddenly) and which questions were encouraged.

Another assumption was brought to my attention by Dr. M in his interview. He

stated that there may be a world of difference in responses to my questions concerning communication in futile situations between the ICU physicians and the medical doctors on the ward. ICU physicians would have a disposition towards pronouncing futility. They live with it. When there is no hope, they are expected to announce that the situation is futile. The families, although they dread the word, may realize the seriousness of the situation and know that it is a possible event. The physician on the floor, however, resident or specialist, is expected to cure the patient. Generally, from the moment the patient arrives in the hospital, the physician, patient and family form a dialogue geared to eventual release of the patient. Futility is not in the normal vocabulary; it's only to be used unexpectedly. In the odd case, physicians might refer the family to see another doctor, whereas in the ICU this is impossible. Because of this option, physicians on the ward may be reluctant to use the term. Patients and family are not usually ready for it. Many doctors are cautious, as I have heard in my research. The consensus was that they accede to family wishes. The patient and family have to be ready. "We have to be cautious." "We have to take it step-by-step." "We watch the response of the patient." "Many do not want to hear it."

A further phenomenon which affects doctor-family communication is the nature of communication itself. Because communication is equated with words, there is a temptation to hold back and control the conversation. The doctor may be protecting him/herself by not discussing the futility issue with the patient. The physician may personally feel uncomfortable discussing death and he, too, hopes conditions may change. Sometimes it is too big a burden for the family to make these choices and the physician

senses that the family wants him/her to make the final decision. Finally, physicians may fear emotional and psychological reactions of the patient, such as depression or suicidal tendencies. The physician does not want to precipitate any such reaction.[12]

Mary Vachon adds a group of normal environmental stressors which may affect physician-family communication. These include fears of lawsuits (Dr. B), intra-group conflict (Family K), inter-group conflict and stress affecting physicians' morale (Dr. D).[13] I would also add that many physicians have a poor education and orientation towards medical ethics and are not trained to handle difficult issues.

In conclusion, I do not wish to leave the impression that most physicians do not know how to communicate and cope with these problems and frustrations. Many of our physicians are astute and fine doctors who are excellent communicators. They have conventional wisdom and the sixth sense for reading their patients' and families' needs which are often unexpressed. This may be part of the "art of medicine". For these physicians, medicine is not only a physical science based on scientific evidence. It is also an expression of humaneness, of understanding people, a recognition of their patients' and families' significance. It is an affirmation that what their patients think and experience matters to them and that they care what happens to them and how they feel about it. I noticed this in many of the physicians whom I interviewed. Dr. B, an oncologist, said, "We see people at their best, courageous, supportive and loving. These are people facing a life crisis." Dr. C, who admittedly described his own feelings, "It depends on my mood... how happy I am that day... Truthfully, I have no answers. Each family is different. Each doctor is different." I recall Dr. E, the geriatrician, who

said, "Time is the key. The physician has to be clear and allow for all questions." Dr. E's questions would include, "What do you reasonably expect to do with mother? From her history, what do you think is wrong with her? As physicians, we believe that the following is the diagnosis. Would you think that this covers the situation? Do you have something to add?" Dr. E would then explain the planned treatment and ask the family if they have any suggestions. The family was made to feel that they were part of the team, an appropriate attitude from her geriatric team. I also remember Dr. G, the surgeon, who emphasized, "You have to know the family. We are never 100% sure." I know Dr. G personally. He sees no more than ten patients a day and gives each patient close to an hour of his time. He is one of the busiest surgeons. I also recall the resident and attending physicians in Emergency who, upon meeting patients for the first time, had the capacity to forge a feeling of trust in the doctor/patient relationship simply by concentrating on some personal needs of the patients.

3. The Family

As we noted in Chapter II, there may be some unresolved problems within the family which the medical team is not aware of. These would include marital conflict and anger which families try to hide. Vachon reports a case of a woman who suffered severe physical abuse, and yet, when confronted by her husband, remained loyal and obedient. Family relationships are very complicated, often symbiotic, feeding from guilty feelings which have never been resolved. Difficult parent/child relationships are also disguised

by expressions of overprotectiveness and a feeling that children have to compensate for not being obedient when, in fact, they were not loved by their parents. The family may also have suffered some recent severe blows such as job loss, a financial crisis, an untimely death or problems involving children. The family may, thus, feel depressed, taxed, paralyzed and withdrawn, unable to face or discuss the situation at hand. Holocaust survivors and their families are a special group which need special attention. The horrors of the past are indelibly inscribed in the memories of the patient. From my experience, only a handful of doctors (usually children from Holocaust survivors themselves) can communicate well with these patients and families.[14]

There are also some assumptions affecting communication which stem from Jewish family values. As noted in Chapter VI, the family is generally over-protective, having strong feelings of a duty to honour their family members. They are also controlled by guilt and expect high achievements from themselves and the professionals with whom they interact. If the family is religiously inclined, great emphasis would be placed on the principle of the Sanctity of Life. The implications of these assumptions touch upon some extremely important medical ethical issues. While physicians may feel a sense of medical futility, the interviewed families would react with great suspicion. "Is the doctor referring to our father's age?" "Is he looking at my husband's quality of life?" "What does he know about my husband?" "What does the doctor know of our faith?" "He talks in terms of percentages. This is my mother. I owe everything to her." "Why did they take away my mother's hope?" "Does the physician want me to abandon my father? Never!" "What kind of physicians would tell my mother the whole

truth without speaking to the family first?" "I won't take this lying down. I want a second opinion." "This doctor has no feelings. He is abrupt and he has no time for us." Precisely because Jewish families are high achievers, there is a reluctance to give up. Precisely because they emphasize honouring parents as a duty, they see futility as abandonment. Because of the belief in the Sanctity of Life, they will not easily accept allowing patients to die. As Jews, we advocate the concept of protecting our family as a duty and because we often feel that we haven't achieved all that is expected of us, a sense of guilt permeates our actions. In conversation with Dr. Bird, he pointed towards two older Jewish traditions: a) the family should be the primary care-givers, and b) when death occurs, families should accept it. I recall, as a high schooler, conversations at home which deprecated our neighbours who placed their parents in the *Moshav Zekenim* (Jewish Home for the Aged) rather than take the responsibility of caring for their parents. In those years it was a *shanda* (shame) in the community for this to have happened. And if a family member died, the expression was *Baruch Dayan Emet. Hashem Natan, Hashem Lakach, Yehi Shaim Hashem Mevorach.* (Blessed is the true judge. The Lord has given, the Lord has taken. Blessed is the name of the Lord.) Now, however, as the present Jewish family is forced to take their parents to the hospital and especially Long Term Care, feelings of guilt, anger and dependency may be introduced into the situation. Families might feel pulled in two directions. On one hand they seek the best technologies available; on the other, they have a deep concern for having given the care of their loved ones into the hands of others. When this personalized care which they yearn for is not forthcoming, tensions may arise, complaints begin and physicians and

hospital are blamed if anything goes wrong.

But while these incongruencies may exist for some, times have changed. Long Term Care is an acceptable fact of life in every hospital. In the Jewish community geriatric institutions such as Maimonides Hospital for the Aged, The Jewish Hospital of Hope, and The Jewish Nursing Home have admission waiting lists of up to three years. The average age in an acute care hospital is close to eighty. Patients are seriously ill. To be hospitalized in Quebec means that the patient cannot be taken care of at home. Often we are concerned with life-threatening illness. The process of hospitization places a special stress on patient-family relationships of all faiths. From this view of Chaplaincy, I have seen the best and the worst of all family relationships exposed at this time. I have witnessed, on the one hand, destructive family patterns, especially when large sums of money are to be inherited, and on the other hand, the most intimate and loving characterization of family members as they care or must say farewell to their loved ones.

The pressures are great and relationships change. A wife suddenly finds herself not ready to cope financially. It was always left to her husband. Children become major caregivers, financially and psychologically. Some children may find themselves in the role of the sandwich generation, taking care of parents and children at the same time.

Often children are out of town and others who are in town haven't the time to spend with the patient. An unmarried daughter or relative may be chosen by the family to take over the responsibilities. The patient who was strongly independent suddenly becomes embittered because he/she needs to be fed or assisted in going to a bathroom.

It becomes difficult to please the patient. Because of these pressures, the hospital and staff are often scapegoated to compensate for the families' feelings.

How, Why and Where the Problems Arise

I have, thus far, discussed some of the major reasons why communication has become so difficult between physicians and families. As government interventions in medical care grew from minor to major proportions due to financial constraints, the Canadian medicare system was transformed from a physician-centred to a government-centred model of care which I call the administrative model. This model has curtailed the traditional role of the physician to a point where many physicians now feel that they are government employees, professionals who are primarily responsible to the government. The hospitals, too, feel this governmental squeeze resulting in a partial takeover by an administration that receives its orders from the government. Consequently, physicians and hospitals are expected to care for patients under extremely pressured circumstances which do not allow or encourage good communication.

I also discussed the Jewish family and the pressures placed upon the family by the administrative model. I looked at the various internal problems and pressures these families may have and their values and attitudes which could affect communication and decisions in end of life situations. These patients and families may be frightened, needing to be understood, supported by physicians who do not have the time to visit and communicate as they would wish. As we approach the following section, it may be

prudent to review questions families and physicians may ask themselves in the medically futile situation. What is going through their minds? Some thinking along these lines may better put into perspective the situations which arise and cause anger and confrontation.

The family concerns may involve the patient's care. Does the physician really care? Does he/she understand our family? Does the physician know how important the patient is to the family? Is the physican really competent? He is so young! Why doesn't the physician give us more time? Does he know our culture and faith? Does he/she really have our best interests at heart or the interests of the hospital? Is the physician concerned with costs? Is the physician telling us the truth about the patient's chances? Maybe we should ask for a second opinion? Do they look at us as nuisances or adversaries? Why doesn't the physician come in more often to visit? Are they going to abandon the patient because nothing more can be done in his/her favour?

The physicians, on the other hand, may be concerned about how much the family really understands about the diagnosis and prognosis. Are they in denial? Why are they so angry and aggressive? Why are they so passive and undemanding? Is the family anxious to be rid of a patient? Do they have ulterior motives? Do they feel guilty? What are their hopes and expectations for this patient? How does the family really look towards the medical profession? Why are they so ambivalent about making a decision? Do they expect the patient to live forever? Do they feel that the illness is a punishment to the family? Why do they not have trust in us? They seem to ask every doctor who passes by.

From the above questions, I note that these concerns are multi-dimensional and are problematic in the communication between family and physicians in the medically futile situation. Because these concerns are very personal, the speakers often talk past each other and are not really attentive to what the others are saying. We become so involved in what we think is important that we cannot fine-tune our minds to what the others are trying to tell us. Further, families may be speaking at different levels at the same time. While they have many of the concerns mentioned above, they can only ask one question at a time. They also may consider themselves as knowledgeable yet lay people, skeptics (doctor shopping) yet trusting, all at the same time.

In listening to the different reasons and problematic areas affecting physician/family communication, I have divided them into five separate sections as shown in the following table. The first four sections include the independent variables, factors which directly or indirectly affect communication. The fifth section is the dependent variable which is the final agreement or disagreement with the planned treatment. Many of these issues overlap. However, I may be better to identify and clarify the problems within this classification. I will also propose suggestions to alleviate the problems and further better communication.

Table 2. Areas Affecting Physician/Family Communication

I	STATE OF THE PATIENT	1. Concern of How the Patient is Doing 2. Age of the Patient 3. Pain and Duress of the Patient 4. Religious and Cultural Background and Holocaust Survivor
II	STATE OF THE FAMILY	5. Family's Ability to Respond to Current Needs 6. Agenda and Expectations of the Family 7. Family's Ability to Deal with Grief
III	SETTING	8. Setting and Timing
IV	COMMUNICATION	9. Comprehension: Agreement or Disagreement with Diagnosis 10. Variations and Modes of Communication 11. Different Reactions to Possibilities 12. Stereotyping of Families and Physicians
V	AGREEMENT OR DISAGREEMENT WITH TREATMENT PLANS	

I. State of the Patient

1. Concern How the Patient is Doing

This concern could be exacerbated from two accounts. First, patients, in general, do not like to complain. When doctors make rounds, they hear from the patients, "I feel much better today." "No complaints, except for the food. When will I be able to go home?" The families see the situation differently. They hear the complaints. They know the patient. The patient will usually not hide the truth from the family. When the family shows their concern, the doctor may feel that they are exaggerating. Secondly,

the short staff situation and different shifts leave the patient and families uncomfortable. Fairly often, one shift is not fully aware of the patient's situation. It's a nagging problem. These problems should be addressed with the patient and family to improve communication.

2. Age of the Patient

This is one of my personal major concerns. We have a tendency to think that the elderly ill have "lived their lives" when they have reached their 85th birthday and it is now time to let go. It may be true for some, but we have to be very cautious not to communicate along these lines. It is one thing when patients say, "enough is enough", but we must not in any way transmit such feelings which are usually picked up by the patient and family. These may be personal biases stemming primarily from a belief that patients should realize that they have become a burden to society. Our wards are filled with patients that are incontinent, wearing diapers, having to be fed, suffering from a form of dementia such as Alzheimer's. It is easy to categorize such patients as less worthy than others who are younger.

A second factor which the elderly suffer from is sensory deprivation, when their taste, smell, hearing, touching, etc. becomes less prominent. I recall an episode which happened to my father. He was admitted for cellulitis in his feet which he had ignored. He was forced to be hospitalized. I looked in his chart. The diagnosis included "Alzheimer's". I was shocked. If you are diagnosed with Alzheimer's you are often

treated like a child. I recognized the doctor's signature and chased him down. "What do you mean by concluding that my father had Alzheimer's?" The doctor looked at me sadly, "Rabbi, come with me." We went to Father's room. The doctor began to ask my father the regular series of Alzheimer questions. My father looked at me and said in Yiddish, "What does this young man want from me? I don't hear a word he is saying." I told this to our young doctor. He said, "I didn't know that. He didn't tell me that he was hard of hearing." I replied, "He doesn't tell anybody. He is ashamed to admit it. Now ask him the questions in his right ear." The doctor moved over to his right side and started asking the questions. My father interrupted, "Why do you talk so loudly? Do you think I am deaf?" We all laughed together. Sadly enough, this is a common occurrence especially when patients are over-medicated.

I want to emphasize the importance of delicacy in communicating with the elderly. They are a weak and vulnerable population. As the government and hospitals emphasize shorter stays and pushing the elderly back to a community which cannot give proper care, we perceive the signal that life and care is for the young, not for the elderly.

Let us look at an elderly gentleman on our 6W Geriatric Ward. This gentleman is 90 years of age. He is an Alzheimer's patient. He hardly recognizes anybody. What kind of quality of life is this? Why bother with medication for his pneumonia? We think to ourselves, "Let him go." However, if we look into the situation further, we see his wife who comes in daily at 8 a.m. to bathe and feed him. She stays to 6:30 in the evening to make sure that he has his supper. How do we tell this elderly lady that he

has no quality of life? They have had a good life together. They were a team. She watches every nuance of his and she feels his love even now. How do you measure love?

Schneiderman and Jecker invoke futility and the right to end life in the following situation. If the patient has lost his/her capacity for rational thought, awareness of their personhood, ability to relate in interpersonal relationships with a capacity to experience pleasure, there is no further reason to extend life. Of this condition, Bleich writes,

> It rapidly becomes evident that the absence of such a telos is not associated only with the terminal, comatose condition or even with the permanent vegetative state, but it is also absent in some states of insanity and mental deficiency. If that line of reasoning is pursued to its logical conclusion, it results in the assertion that *mutatis mutandis*, the life of any person not capable of experiencing that telos may be snuffed out with moral impunity. Euthanasia would then become morally acceptable in situations not involving terminally ill patients. Applying such criteria, permanently and severely mentally disabled or retarded persons would be candidates for euthanasia.[15]

I would add one more category. I think of many of our elderly who fit in Schneiderman and Jecker's criteria. Can we imagine a society which would permit euthanasia under these conditions?

Again, I conclude that the full picture is not so bleak. There are geriatric physicians that are excellent. I recall one physician in his 50's talking to a 90 year-old lady in the corridor on 6NW. She was hard of hearing, bent over in a wheelchair, and the doctor was on his knees talking to her - not about medication, but just about small talk. The patient was beaming and so was the doctor. I passed by, "Doc, I wish I had a camera."

3. *Pain and Duress the Patient May be Experiencing*

This is associated with variable #1. Patients, in their desire to do well, do not complain. Further the tolerance of pain is different with each patient. The physician and nurses are usually aware of the pain and try to alleviate it. However, as in the case of the family of Mrs. L, there are different concepts and gradations of pain and embarrassment for patients and families. Families who witness the patient's suffering easily blame their frustrations on the health care system and equate notions of futility with lack of care and abandonment by the staff.

4. *The Need to Know How People of Other Faiths, Cultures or Holocaust Survivors Adapt to the Situation*

As I pointed out, people of different faiths and cultures may adapt differently to end of life situations. As our society becomes multi-cultural, we realize that we cannot generalize about what life, illness and death mean to a patient and family. More than ever, patients and families have to be individualized. We also deal with biases, cultural and personal. Communication patterns may differ in various cultures. In some cultures such as the Anglo-Saxon, it is normal for a physician to communicate freely and openly. As we pointed out, Jewish people and others expect the physician to be very cautious in what he says and to protect the patient. Personal biases are also prevalent. I think that black patients would be more comfortable with a black doctor. Jewish patients whose mother tongue is Yiddish, or who are Holocaust survivors, may also prefer a Jewish

physician. Within the Jewish community, the concept of time may differ from other cultures. For the Jewish Chassidic community, a wedding invitation or community program scheduled for 8 o'clock sharp means not before 9 o'clock. It would be insulting for anybody to begin the wedding or program at 8 o'clock. This is true for many communities such as those in South America or Africa. Thus, physicians may be angry with patients who come late for appointments, while it is normal for people of different cultures. Further, it is extremely difficult in a short-staffed busy hospital to have any lengthy communication when the players are from different cultures. The Montreal Children's Hospital has developed a special department which patients and families may consult to overcome this problem. The Centre Hospitalier Côte des Neiges has researched and developed pamphlets on the needs and expectations of people from different cultures in the medical setting.

Patients and families who survived the Holocaust are extremely sensitive and may easily misread what the doctor or nurse has told them. They may see the busy hospital as impersonal and uncaring. It is important to communicate softly and in a compassionate fashion to this group of patients and families.

II. State of the Family

5. *Ability of the Family Members to Respond to the Current Needs of the Patient*

There are four issues involved with this concern. First, many families are out of

town, fragmented, etc, and patients are often alone. Second, some family members are extremely busy or elderly and cannot take care of family members if they were to be sent home. For instance, how do you tell a lady who broke her leg, who may be divorced with three children and is being sent home, "You have to stay in bed and keep your leg up on a cushion on a high level." Physicians are often not aware of these situations, having not been in touch with social workers, and oftimes families do not wish to disclose some of their own personal problems or feel it is wholly their responsibility. Third, the stability of the family is at risk if the patient is the major caretaker of the family. Fourth, there may be different skills which may have to be taught to the family and elderly spouses cannot be expected to learn these skills. The key to solving these problems lies with Social Services. There are some, although not enough, resources to assist these patients and families such as the CLSC, Jewish Family Services and Jewish Support Services for the Elderly.

6. Agenda and Expectations of the Family

There are aggressive families such as Families D and F who were quite demanding in their expectations. It's almost as if these families have their own agenda and if the staff does not comply, a confrontation could easily develop.

This phenomenon is a fairly frequent occurrence in our hospital. Final major decisions are usually in the patient's domain. If the patient has been fully informed, the decision to continue a treatment belongs to the patient. Sometimes I hear, "Rabbi, they

want to give me chemotherapy but I have had enough." On other occasions, I note an ambivalence in not knowing which course to take. These are extremely difficult situations which Dr. B referred to as involving "heroic" decisions. It may be more problematic for the incompetent patients and their families who do not wish to cooperate with the physician who recommends a specific difficult treatment or the cessation of further treatment. The family, because of cultural or religious reasons, may insist on continuing life-support and further aggressive treatment. (Families H and K)

I believe it is only fair for families to expect reasonably good treatment from the physicians and nurses in their approach to the patient. Sometimes physicians lose a sense of priorities. I recall a family complaining, "Rabbi, the physician didn't show because he was busy with his research. What kind of excuse is that?" Or I may hear, "The physician did his rounds first and saved me for the end of the day because he wanted to give us more time. In the meantime my mother died." The physician meant well, but for the family, he was a failure. From the physicians I often hear, "Rabbi, this family is unfair. They want me at their beck and call." Or I may hear, "Rabbi, they're unreasonable. They're telling me what I should do. They have *chutzpa*!"

Again we see the importance of good communication. From the beginning, ground rules have to be laid. Families cannot have physicians available to their wish. Physicians do have to set priorities. In the last-mentioned case, if the physician would have advised the family that they would be contacted later in the day, perhaps the urgency would have been explained and at the very least, communication would have taken place.

7. Families' Ability to Deal with Grief

This is sometimes difficult to identify especially in the early stages of communication. It is only after the family has absorbed the bad news that we begin to note some family dysfunction as in the cases of Ruth and Family M. The problem is exacerbated if we do not continue to communicate. We drop the bombshell (bad news) and expect the family to adapt. It isn't so simple. We have to continue speaking, and making referrals to appropriate resources. I recall a rather extreme case where a daughter refused to accept her mother's death and climbed into her bed with her "to keep mother warm". We called in social service and psychiatry to assist in calming the daughter and made certain that all lines of communication remained open. A more common instance is when a spouse keeps her husband's room and wardrobe in order as if she is expecting her husband to walk into the door "any minute now".

III. Setting

8. Settings and Timings of the Communication

The setting and, more important, the timing often makes good mutual intelligible conversations very difficult. This happens when doctors are harried for time. Perhaps they have an agenda and want the families to fit into this agenda. It doesn't work. Families are sensitive. Sometimes families need more time, as emphasized by Dr. E and

my experience with Family H. There is an inclination towards making quick decisions. Perhaps we have to elicit the feelings of families to see if they are ready to let go before we embark on engaging the family to make a reasoned decision. In all fairness, I have to make allowances for physicians who may be tired and not in the mood to carry on a lengthy conversation with the family. The family, too, may be difficult, nagging, repeatedly asking the same questions. They may also be inconsiderate of the needs of other patients and families who must also have time to speak to the doctor. The answers from physicians may be curt and misinterpreted by the family as unsympathetic.

Ruth Purtillo suggests guidelines for health professionals to make the best use of the time spent with the patient. I list these guidelines and add parenthetically the word "family" in addition to "patient". It is not an easy task for the family because they may feel that they are being forced into a time slot. The challenge of the physician is to be compassionate but firm so that the family can appreciate the time given to them. The following are the guidelines.

1. Remove the patient from hospital traffic and other areas where distractions are likely to occur.
2. Sit down when talking to the person to give the impression that he or she is the only patient in the world who needs care.
3. Refrain from calling attention to how busy you are, or you will seem to be paying even less attention to the patient than you are. If there was an unavoidable delay in getting to the patient, explain why; or if you cannot hide your distraction, explain that too.
4. Approach the patient slowly and graciously, even though you may have to run to the patient's room to be on time.
5. Look the patient in the eye when conversing instead of glancing all around the room. A lack of eye contact communicates lack of interest and further increases the patient's feeling that his or her time with the health professional is being dissipated.
6. Protect the time that you have with the person by telling other people in the area

> that you are busy and will be happy to talk with them later. The patient who is scheduled to spend 15 minutes alone with the health professional, but shares them with ten intruders or telephone calls, will feel more cheated than one who spends 5 uninterrupted minutes with him or her.[16]

IV. Communication

9. Different Understandings of the Diagnosis

This may be caused because the doctor is not speaking on a level which is readily understood by the family or because the family subconsciously only wants to hear good news. Even as many families are explained the difficulties of the situation, they cannot seem to grasp an understanding of the problem. We saw this as a clear example with Dr. C, who explains the illness with diagrams and notes. Still, he said, "Fifty percent did not understand what I explained." The families may also be intimidated by the physician or paralyzed with fear.

10. Physician and Families Typically Talk in Different Styles

As a result of these different styles, they do not talk in ways easily comprehended by each other. We have mentioned above that because of the level of the playing field, physicians have a tendency to talk down to patients. This gives them an authoritative voice and they tend to monopolize the conversation. They also may use technical terms which are above the family's understanding (Ruth and Family D). Sometimes, doctors

and families and patients do not fully and clearly voice their concerns. Bird refers to this problem as being "morally mute". Often patients and families fail to ask the medical staff what they mean when the doctor uses medical terminology. This is especially true when there may be inter-family disagreements. In such cases, families are overly concerned with internal problems. Further, the players involved are often not listening to each other. This happened to Miriam in Family A. This was her major complaint and the complaint of most of the families I interviewed. It is as if the family and the physicians were trying to communicate while on different radio wave lengths. The physicians see the situation from a scientific viewpoint while the families are often emotionally involved. We must bear in mind that each conversation has two components including the agenda and tone of conversation of each party. Both are considered the essence of conversation and are extremely important in the hospital mileu. Because of these differences in comprehension, concerns are not expressed. The families will ask the nurse or medical residents to explain what the doctor said. Some families sense that the physicians will not encourage questions. The result is a morally mute situation where physicians and family do not voice their concerns openly.

Finally, I have also noted from Ruth in Family D that interpretations of good communication may be very complex because of the psychology of the family and that families have different concepts of what communication is all about. Sometimes there may be a sense of normalcy in what seems to us as strained difficult and poor communication.[17]

11. Physicians and Families May Have Different Notions of Probabilities

Because of the physician's experience and knowledge of the relevant research, the physician may advise the family against treating the patient aggressively. I have noted, on many occasions, that families have different concepts of what the probabilities are and different feelings about the percentages that are quoted. Further, many providers give different messages to the family. Families also have a tendency to involve many physicians.

I offer a fairly common scenario at the "Jewish". The staff doctor, a cardiologist, is presenting rounds on the ward. He reports, "Our patient, Mr. Smith, is slipping. Has anyone spoken to the family about DNR orders?" A resident replies, "I've charted that the family wants everything done including sending Mr. Smith back to the CCU (Coronary Care Unit)." The cardiologist says, "This is crazy. He's not a candidate for the CCU. There is really nothing that can be done anymore. When the family arrives later this morning, I want to speak with them." At about 10 A.M., the unit agent (secretary) advises the doctor that the family has arrived. The doctor calls the family, consisting of two unmarried daughters, into the conference room. The girls are frightened and anxious. The doctor speaks kindly and softly. "I know you're going through a difficult time, but father is very ill, as you know. What do you expect from us at this time?" The girls reiterate their position. "We want everything to be done, including sending him back to the CCU." The doctor replies that "it is not feasible to treat your father aggressively any more. It's come to the point of just keeping him as

comfortable as possible." The girls answer, "We have inquired about his chances. Our cousin, a physician in Toronto, told us that there is about a 10% chance to survive CPR." The cardiologist returns, "I don't know where these statistics come from. I speak from 35 years of experience. It would be cruel to resuscitate him. Have you any idea what resuscitation involves? Your father is so frail. And I think it is unfair for your cousin to give you advice when he hasn't seen the patient." The girls respond, "But doctor, you don't understand. Father is all we have. We don't want to lose him." The doctor looks at the girls, "I understand. I understand."

There are a few issues which could be explored. First is the issue of statistics. From the cardiologist's view, statistics are not very meaningful when the patient is so frail and his heart is in failure. There are so many physiological variables to consider before deciding upon a total statistical value on a patient's chance to survive CPR. For the physician, his knowledge of cardiac medicine and his many years of experience are his guide to treatment.

The doctor in Toronto, a family member, sees it differently. He knows the patient and the surviving family. He tries to be as gentle and encouraging as possible. He knows that the cardiologist in Montreal is an expert and is theoretically right. He does not want to aggravate the girls in their anxiety. I have seen the same attitude from my research with many of our physicians at the Jewish who go along with family wishes in difficult situations.

For the girls, although they quoted statistics, it was not the major issue. They were hoping for a miraculous cure.

12. Stereotyping Patients and Families

There is a tendency to view the concern of others in stereotypical terms. This is probably a normal response when we see so many patients where doctors describe them as CA, CHF, Geriatric, etc. Families, however, want to feel individualized. They place a picture of LTC (Long Term Care) patients above the bed, trying to impress the staff that the patient was once young and vibrant. Further to the stereotyping of patients, they also tend to stereotype physicians as cold and uncaring. Because of these labels, patients and families shop around for physicians "who care". Endless waiting for physician appointments, packed offices with patients, families anxiously waiting for hours in hospital corridors until physicians do their rounds and finally only seeing the doctor for a few fleeting moments, all breed a sense of mistrust which discourages communication. We also tend to stereotype attitudes which could lead to a trivializatio of concerns which are most important to families. The family of the patient whose life is failing is often approached by the staff, "We think you might want to consider Father or Mother dying with dignity. Why should we prolong the situation?" While many families would agree, others would say that there is no dignity in death. Death in itself is an indignity. They may see dignity in death only in the environment where family physician and nurses are there till the end. Lowering a respirator or stopping the feeding in the PVS patient does not mean that the person has died in dignity.[18]

V. Agreement or Disagreement with the Treatment Plan

These are usually issues initiated by the family after they have understood the seriousness of the diagnosis. Even at this point, families will still only hear what they want to hear. They may begin visiting many doctors and go on the internet, etc. When physicians sense this attitude, they do not want to "burst the bubble of hope" and the family does not really get the full information. Further, physicians in general do not like to suggest to their patients or families treatments which they feel will not help.

Because of the above concerns, we must take into account the basic personality of the family of which we know little. To accomplish this, we go into a responsive mode. We listen to the family and answer their questions. Gradually we gain their trust. Families are not felt to be intruders but part of the team. This is very important because they are dealing with their own grief, sadness, guilt, anger and depression.

As discussions regarding treatment procedures proceed, we continue in this listening mode. The families may fear surgical interventions, searching for non-surgical alternatives. They may fear chemotherapy and its side effects and search for second opinions. They may ask for statistical information on probabilities of success rates with the proposed procedures. In all events, we assure the family that pain will be controlled and that the patient will not be abandoned. My major point in this area of concern is that we should not feel that families are there only to receive information and listen to us, but that we are there to listen to them and receive information. Families should feel that they are an integral part of the patient's healing process.

In summary, I have listed twelve areas of concern which directly or indirectly affect physician-family communication. I have tried to examine these concerns from both the physician's and the family's points of view. These twelve variables represent the center stage. When we focus on the patient and family these variables are our major concerns.

From my interviews, however, I have noted other factors and forces which play a major role in the communicative process. These included the physician-family perception of futility, Jewish family traits and values, government and hospital pressures to release patients as quickly as possible and the physician's and family's ability to listen and communicate. Thus, we begin to note the vast areas of concerns as we enter the communicative process.

Good Communication - A Collaborative Model

In the development of my collaborative model, I have turned to Frederick Bird's Seven Features of Good Conversation[19]. I will first examine Bird's model in view of the above assumptions and communicative problems I have encountered in my study. I will then refine Bird's approach to fit into my own collaborative model which would, hopefully, avoid and/or alleviate many of the roadblocks preventing good conversation in the medically futile situation.

In his comprehensive thesis, Bird elaborates upon moral silence, moral deafness and moral blindness as the major factors in stifling any meaningful moral communication

in the world of business. Bird explains that the underlying causes are human responses by the players involved and that through good open communication, the issues can often be solved.

Moral silence is when people are morally mute and do not communicate their moral concerns when such communication is appropriate. This would include asking no questions, offering no dissention or opposition, being silent and not holding others accountable for their actions and not speaking up for their ideals. Moral deafness is when people do not listen or respond to moral issues which have been presented to them. This occurs when people are inattentive and lack the moral sensitivity to consider the presentations of others. These are persons who are not ready to seek out or hear any bad news. Moral blindness is described as short-sighted, far-sighted or tunnelled vision in people who lose sight of the issues, fail to envision consequences or recognize the moral dimension of the issues. They tend to stereotype, show bias and are self-deceptive.[20]

If we consider Bird's model which explains poor communication patterns in business, we can easily transport virtually all his observations to the present hospital situation, especially as we consider the administrative model as discussed. Physicians are morally mute when they protect each other, do not blow any whistles or speak up to the noble ideas declared by the medical profession. Sadly, perhaps, hospitals have become business institutions, run by governments, and in the USA by insurance companies or hospital conglomerates. Physicians are morally deaf when they lose the capacity to listen to patients and families. Perhaps it's the nature of the hospital situation and the administrative model. Families are expected to listen to the doctors, not the

other way around. Families do not confront physicians as Ruth did. They become mute when they "whisper" their concerns to the staff. Patients and families are now on the physician's turf. Who can argue with the physician? Thus, the family is expected to remain mute and morally silent. The vocal families in our research were problematic to the staff primarily because they expressed their feelings, opinions and disagreements. And when exchanges are made, they are, as Bird explains, "mutual monologues" where those involved do not listen well and they do not directly address what the other has said.

On the other hand, families are morally deaf when they refuse to listen or entertain any bad news about the patient. They may rationalize, believing that the physicians have given up too easily. They (these physicians) are considered incompetent. They believe the patient has lived his/her life or have decided that there is no quality of life left for the patient. In fact, this is the crux of my thesis. Physicians and families see their personal arguments as moral issues in which each side is not listening to the other's arguments. The physicians see moral deafness in the family, claiming that the family wants to block out all the bad news and that the family refuses to see the futility in the situation. The family sees it as a blockage in physician understanding of their situation and the lack of willingness to continue treatment of the patient, for sometimes miracles do happen.

Bird argues that the practice of good business ethics can be best developed through effective give and take communication. In order to remedy moral silence, deafness and blindness, his ethics does not focus on what is right or wrong. He sees ethics as a process, a social activity and communication within the organization, which

when used positively would help people maintain agreements and help each other overcome their sensory incapacitations. He describes "moral discourse as any communications in which people voice moral sentiments or convictions, whether they do so using overt moral language or not".[21]

Bird's approach fits well into the hospital organization where decisions are made from macro allocations of resources to the micro decision process involving each patient. We, too, in our hospital community are very much involved in moral discourse, whether we use moral language or not. Our hospital administration and Board are constantly lobbying government, regional councils and universities to get specialized programs. From a tertiary care hospital we strive to become known for quartenary care. All this takes place in a political arena where one hospital vies with another to get special grants or programs. Strategies and representations are made at the highest level. All these actions and decisions are connected to moral considerations. Are we fighting for the glamour of being the only hospital in Montreal which does retinal surgery or are we considering funds to cover the cost of a gruelling long-term care program? On a lower level, we can turn to our Equipment Prioritization Committee which oversees hundreds of demands for extra equipment from different departments. A dozen individuals - from physicians to nurses and administration - try hard to be fair when they make the decision. Other than formal requests, there is little communication between the departments and the committees.

Moral silence, deafness and blindness can be expressed in many ways. Families can become morally deaf and blind when they say, "It's **my** mother. How would the

doctor react if it was his mother?" The patient may intimate or even express overtly, "I don't want to know the diagnosis. Just get me out of here." Hospital administration may argue, "What do you mean, the patient is competent? He's over ninety. It's crazy to have him on dialysis. It's not fair to our staff, other patients, and society in general."

Doctors, too, may have their difficulties working with terminally ill patients. The concept of having to confront a patient and family honestly demands moral consideration of how one does this. While some would say that we have to be one hundred percent truthful from the start, others would suggest waiting to see when and if the patient will be ready to receive the news. Finally, some would say that there is no point in telling the whole truth. Always leave the patient hope for survival. My research pointed to the second group as the most common.

Bird's Model and the Hospital

I now turn to Bird's Seven Features of Good Conversation while recognizing the difficulties in implementing them in a hospital setting - especially when we involve the terminally ill patient and family. For my purpose, in fitting Bird's model into the hospital setting, I will change the order of the seven features in order to see it as an systematical approach.

Good Conversation Requires Attentiveness

The first feature is that speakers are attentive. Bird explains, "we listen with half an ear. We get a sense of what is being said, but remain largely insensitive to innuendos, mixed messages, and leaps of logic. We are not fully present... All that is required is that we respect others as human beings enough that we are willing to pay attention to what they are saying to us."[22]

In the hospital setting, families and patients often feel that the doctor has no time to listen, only to explain. It is as if he/she has one foot in the door and the other outside. The workload may pressure them into manipulating patients and families to listen, as in the case of Family B. Thus, there is hardly an open-ended conversation. Patients and families begin to analyze the tidbits of information they receive. Moreover, patients and families find themselves treated by many physicians, including residents on rotation. It's confusing. With which doctor should they speak? Who is precisely in charge? In the end, families tend to grab the attention of any doctor that will listen, it's the best that they can do. Families, too, are not attentive. In their anxiety, they focus only on parts of the conversation. They hear, "It's futile to continue." "Time to let her go." "We can't help any more." The rest is a blur. They are in a selective listening mode.

Adding to this feature of requiring attentiveness, I suggest returning to some of the basic concepts in communication. First, the setting has to be right. There should be privacy, sitting arrangements are face-to-face in an effort to minimize any

psychological distancing between physician and family. It can be in the patient's room if the patient desires. It doesn't have to be a lengthy session. If everyone present shows that they are listening, and the doctor encourages questions, then this initial meeting, which is extremely important, can build a sense of trust between family, patient and doctor. I have always argued that it's the process that counts. It shows that we are sympathetic and care. This is most important to patient and family. Second, because many physicians and residents have probably seen the patient and family, it is best if one doctor and nurse are chosen to sit and talk to the family. They should be the official representatives of the unit and medical team.[23] The family and team will be apprised of this. Families should also have one or two representatives who do the talking. It would be best if both hospital and family choose the best communicators so that they will be clearly understood. Any further meetings could take place with either doctor or nurse as representative of the team. Third, ground rules have to be laid. Doctors and nurses should not be at the family's beck and call. These rules are made at the very end of the first meeting. "We know you are anxious, but you also know that we care, although extremely busy. If you feel that you must talk to us, leave a message with the unit agent (secretary) and we will get back to you as soon as possible. Try to prepare your questions in advance."

Good Conversations are Recognizable

Bird explains that "it is important to speak up and not just whisper our concerns...

In addition, if we are to be vocal, we should not mask our feelings. If an issue is important to us, we ought to express the outrage, compassion or concern we feel."[24] This rule, in the context of the doctor-patient-family communication which we have described as favouring the doctor, becomes very important to the family. It is not easy for the family and patient to speak up. How does one argue with the doctor? What happens when the patient and family do not share the same mother tongue or fluency in language? Further, physicians have a tendency to speak in medical terms while patients and families understand very little of what the doctor said. While it may be impressive and important for the doctor to use medical terms, it leaves the family confused.

Because of these concerns, I would add the following to this feature. First, we have to try to get the patient in early end of life discussions before he/she comes into the hospital. While I do not think it's appropriate to initiate these discussions with Jewish patients while in the hospital, it is much easier for the patient to discuss these issues when they are outside. I believe, however, that a living will (as it is called) has become an accepted fact of life and most important for patients and families. If patients decide to change their minds in hospital, this is their choice. However, we have a starting point and decisions with patients and families can ensue much easier having already discussed these issues before. Second, with regard to the physician's inclination to speak in medical terms, Charles Olweny, an oncologist from Winnipeg, supplies the use of analogies to his patient's questions. For instance, to the question of "What side effects will I have to chemotherapy?" Olweny would explain how chemotherapy works. He

would describe bone marrow as a factory which manufactures the different blood components. When the factory develops problems, the chemotherapy is there to supply the shortages created by the problem. To the question, "Doctor, what are the receptors you mentioned?" Olweny would describe how doors and windows are there to allow guests some fresh air to enter a home but sometimes undesirable elements enter as well. Olweny, in his approach, was stressing not only that communication should allow for the interchange of information but it should enable and encourage an engagement of feelings.[25]

Third, in cases of patient incompetency, the family must focus on the patient. What would Mother have wanted? This is a key point which has to be stressed sometimes over and over again. This was Mother's informed choice and as children and family they have the obligation to honour her wishes. Of course, this should be honoured in two ways. If Mother does not want to be kept artificially alive or if she insists on being kept alive under all circumstances, her wishes must be respected by the family. This is the most contentious issue in the futility debate. As noted in the first chapter, the physician argues that "the family has no right to impose their personal wishes on my professional obligation as a doctor". The family argues, "the physicians have no right to impose their professional wishes on our personal obligations as family members". This is the challenge of the communicative process. If communications are going to be recognizable, then we have to attempt to address concerns directly stated by the other, otherwise we have by-passing monologues. If we proceed with good communication, we may convince one of our disputants to gracefully accept the other's

position. From my research, in cases of intransigence, most physicians would accede to family wishes.

Communications are Rational

The third feature is that communications are rational. This may appear simple, but it's not an easy task. Good conversation must be made comprehensible to others. This is quite a challenge. If we recall the words of Dr. G., that physicians have a certain charisma, then social prestige becomes very important. Thus, physicians may enjoy mystifying their audience. Bird explains, "Executives, consultants, priests, and gurus are all tempted at times to assume mystifying stances because of the way these poses enhance the authority of their visions by rendering them other than ordinary."[26] Thus, some physicians may distort the perception of possibilities and misrepresent the diagnosis in their efforts to impress the family. Furthermore, some physicians are poor communicators. They never learned the art of communication, believing that it is unnecessary. They are unpolished, blunt, brief and even crude at times. Amazingly, many physicians still take this approach. They refer to this as honesty, often speaking firmly, leaving little room for hope.

Good conversation is also reasonable. However, what is reasonable in one society may be unreasonable in another. What is proper to one faith could be considered cruel in another. Family members, even within the same faith, may have different values. Bird recognizes these differences. The major point is that good conversations should be

thought provoking. He writes, "Thinking leaves us to examine assumptions, review evidence, explore possibilities, imagine hypotheses, weigh arguments and consider other points of view."[27] We must also understand that communication is different in the ICU than in other medical units. There is rarely an opportunity to ask for a different doctor in the ICU setting where they all work as a team. Communication may also be different in obstetrics which has very few medically futile cases compared to oncology which has to do with futility on a daily basis, just as in geriatrics.

In view of these concerns, I expand on this feature of rationality and reasonableness. First, in the medically futile situation, the team should accentuate to the family the physiological aspects of futility which are closest to value-free. The discussion could include what the family may expect of the patient if he/she survives. They should avoid any use of terms concerning the lack of quality of life which are value-laden. This strictly belongs to the patient and family to decide upon. For them it is the crucial issue. Sometimes it takes time for the family to absorb the information. As they witness the deterioration of the patient's health, they will decide if they are prolonging death or life. During this time, the team continues to repeat the physiological perspective to futility while continuing the treatment. Second, all considerations, costs and resources should be deleted from futile discussions.[28] If it is brought up by the family, they should be reassured that it is not a consideration for the patient's treatment. Third, we should allow, and on occasion, even suggest that the family obtain a second opinion. Although many physicians feel psychologically threatened and upset with the thought, families could find comfort in the suggestion. It shows that the team cares and

this is a source of comfort.

Communications are Honest

The fourth feature says that communications should be honest. Bird says it clearly, "To the degree that we suspect others of lying, it becomes difficult to continue with ongoing, unfolding conversations and it becomes impossible to reach norm-setting treatments. If we think that others may be intentionally deceiving us, it is hard to know where we stand."[29] The problem with truth in the medically futile situation is that it involves some powerful value judgements. For the players involved, there is no simple truth. Truth cannot be separated from the doctors who wish to be honest, the patient's hope and expectations and the family's wish to protect the patient. Thus, there can be three truths, depending upon who is speaking and listening.

From the philosophical view, one may choose Kant's position that there is a categorical imperative never to lie under any circumstance. We may also turn to a utilitarian position which tells us that we may lie under certain conditions. Sissela Bok argues that "it is morally wrong to lie, except in cases where life or survival is clearly at stake."[30] Thus, in the medically futile situation, we may say that there is practically no chance of survival and, therefore, insist on telling the full truth. But this is not so simple. Kant's homeowner, who has to tell the truth about the soldier he is hiding, is not a wife of fifty years who has been caring for her husband daily for weeks on end watching her husband die or a father or mother of a child who is deathly ill. He is not

a loving daughter watching a parent close to death. He is not even a physician who has taken care of a patient for years and is afraid psychologically to upset his patient, fearing that he will hasten the patient's death.

Bird takes a position that, in certain cases, evasion may be a justified tactic.[31] The point is just not to lie. The doctor can say, "We do not know for certain what will happen" - which is a truth. The family may say, "We are with you, we love you and will not abandon you. We can assure you that we are doing the very best that we can" - which is a truth. The patient may then think to him/herself, "I'm in God's hands." There is a delicate balance which we have to tread. The wrong words said to a hopeful patient can be razor sharp. We have to choose our words carefully.

We also have to consider the different cultural concepts of truth-telling. There are many cultures in which withholding the truth is a natural response. Telling the truth may be considered cruel. The consensus of my research among Jewish families is that we have to weigh the circumstances carefully, making certain that the patient is ready to receive information and only given as much information as they are ready to receive. The families, however, may want to protect the patient and may be uncooperative. It then becomes a difficult situation.

Further to Bird's fourth feature of honest communication, the major issue is establishing trust between doctor, patient and family. Although some patients do not want to hear the truth, others generally want to know the exact situation. This has to be explored. We should not come into a patient's room insisting upon telling the patient everything without having thoroughly examined the appropriateness of such a discussion.

The family, however, should be told the full truth, despite the objection of some family members who may want to protect a surviving parent. Second, if the doctor is of another faith or culture, he should acknowledge this. He could say, "Look, I'm not Jewish, Italian, Greek, etc and I would not want to do anything that would upset you." This establishes trust.

Third, there has to be full and frank discussion with the family, otherwise we may prolong family anxiety making it difficult for them to make a rational decision. Some families may have unrealistic hopes. In my experience, we should not initially dwell upon changing these hopes, although we would want to see the family refocus their expectations. This is not easy, especially with a distrustful family. If we are consistent and repetitious about the medical situation, it will give them an opportunity to absorb the reality and comprehend what is happening. If the family asks for some experimental treatment, it should be considered, providing the medical team deems it feasible. The team should explain clearly why the treatment may not be appropriate and why others are more appropriate. We have to show that we are trying to exhaust all feasible procedures. Finally, families should be individualized, made to feel important. Sometimes they feel that others who are influential are getting better treatment and are getting access to resources unknown to them. Even if the patient has a living will, it should be discussed with the family and all treatments explained. A living will is not the end to discussion. We also do not make any assumptions of what families want to hear.

Speakers Keep the Promises They Make

This is perhaps the most important feature of good conversation. Bird says, "Promise-making and promise-keeping are the heart of good conversation... We shy away from engaging in these kinds of conversations with people whom we judge to be unwilling or unable to make and keep agreements with us... We may judge them to be incorrigible liars."[32] In the medical doctor-patient relationship promises are especially significant. The patient counts on the doctor and nurse. He/she is almost totally dependent upon the medical staff. Thus, when a promise is made, it is part and parcel of a contract. There is nothing more disappointing to a patient than a promise not kept. When this happens, we show that we do not care and caring is the bottom line for patients and families. Caring is the feeling families and patients have when promises are kept. "I'll see you later in the day" - is a promise. "I'll phone you the minute the test results come in" - is a promise. The patient sometimes anxiously awaits test results. He waits for the phone to ring. People call him to ask him about his welfare. He cuts them short. "I'm waiting for an important call. Forgive me." The call never comes in. He thinks that "the doctor is too busy to be concerned about me. He really doesn't care." The nurse, too, says through the intercom, "I've got your ring. I'll be in to see you in a few minutes." I come into the room and I hear from the patient, "Rabbi, it's been three hours and she still hasn't showed up."

The doctor and nurses control the patient's agenda. Assuming, at best, that the results were delayed, the doctor may say, "Well, I'll see the patient tomorrow and tell

him that the results didn't come in." He could also phone the news to the patient, or he could have fully kept his promise and visited the patient. The nurse, too, could have advised the patient of her delay. The key is trust, faith in the doctor and nurse. A patient can lose faith. He lies in bed and his mind tends to exaggerate. His fears will overtake him. The doctor has lost the patient's trust. He feels that the doctor and nurse are just going through the motions.

In a medical situation, I would take Bird's feature a little further. It doesn't have to be a promise. It can be a word. The patient is a captive on the ward. The bed, gown, and whole situation is very unfriendly. He hates it. He looks for an encouraging word. If the doctor and nurse do not abide by their word, the patient can feel abandoned. It gets worse when a doctor disappears. It, too, is like a promise that is not kept. The physician may be challenged by the futile prognosis. Death represents failure and the temptation is to ease out of the situation. I am reminded of an article by Dr. Patrick Irvine who made it his business to attend the funerals of his patients. He writes:

> The doctor's visit does two other things that I have come to believe are very important. Our presence adds credibility to the sense of worth that family members gather about their loved one. (He was important enough that his doctor came to the funeral.) It is a very consoling thought. And, secondly, family members regard the physician's attendance as a demonstration of caring for the person who died - that the doctor views his/her patient as more than a business client, consumer, or scientific curiosity with an unusual disease; that the patient has value as another human being.
>
> Most of all, the funeral helps me bring *living* and *medicine* into the proper perspective. In a special way, it gives me perhaps my best understanding of how that person fit into his or her community, and how medical care fit into that life - on the patient's own ground rather than on my medical ground - away from the demeaning patient gowns, the sterile professional uniforms and the white lights of the intensive care unit. The funeral brings that person back home to the community to rest; we are

part of that community too.[33]

I add one major consideration to keeping promises. Families and patients are very concerned about pain at the end of life stages. We try to assure them that there will only be a minimal amount of pain which we will try to control. This is a given in all end of life situations and often a verbal promise to the family. As the health team manages this pain and suffering, it should not fear any legal liability. Pain is debilitating. Pain causes sleeplessness, loss of morale, fatigue, irritability, depression, and anguish about continuing life under such conditions. A physician's fear of drugs being addictive or hastening death is, in my opinion, inappropriate in treating the terminally ill. There is a difference when we use drugs to alleviate pain as opposed to physician-assisted suicide. The former is palliative medicine. The patient and family lose complete trust in the team when pain is not controlled properly.

Exchanges Remain Civil

In introducing this feature, Bird explains,

> Good conversations are civil. Minimally this means that we are expected to be polite and courteous and to avoid directly insulting or slandering conversation partners... We are expected to avoid excessive displays of anger, self-pity or other emotions that may derail ongoing communications. We are expected to act with decorum, to wait our turns to speak and not to interrupt others.[34]

Most families, indeed, act and communicate civilly with the health team. It's a humane sign of respect for people, the goal of our society and culture. We must also be aware that the concept of medical futility may vary culturally. In addition, within the

limits of civility, people may still express strong emotions. It is just a matter of how they express these emotions. Sometimes, however, the emotional atmosphere engendered by medical futility makes this extremely difficult as I have seen in my research. Patients and families can become extremely upset, crying, showing anger and bitterness. This is often displayed towards the doctor, nurse, a family member, or hospital in general. Decorum, too, can be difficult. Families and patients need to digest the words concerning futility. Shock and disbelief can set in. Acceptance may come last. It's difficult to talk of civility with these families. We try to show compassion and empathy. As we deal with families from varied backgrounds and cultures, civility could be a relative term. In Middle Eastern countries, one could expect breast-beating and wailing after futility discussions with the doctors. Families with lower standards of education may also be aggressive as their way of becoming defensive and face an impending disaster. In order to keep the calm, we may call a person whom the family respects to help explain the situation. Sometimes an interpreter is necessary. We also call Social Service, the chaplain and as many people as possible to defuse a difficult situation. Occasionally, it can become very painful for all involved.

Conversations Move Forward Reciprocally

The seventh, and final, feature of a good conversation is that it moves forward reciprocally. Bird explains, "good conversations are reciprocal. They unfold over time as parties respond to each other in a give and take fashion. No one party completely sets

the agenda of what is discussed. No one party is allowed to establish the feeling, tone of the interaction. All parties are given room for saying how they would like the communicative interaction to proceed." "As participants in reciprocating open-ended interactions, conversants do not insist on having the last word."[35] This rule is probably the most difficult to follow in the impasse of the futile situation. The major problem is that families and physicians have different agendas. The purpose of the conversation is to convince or persuade or manipulate the other parties to agree to their personal points of view. Each side wants the last say. This is especially true when confronting a family who argues from a religious point of view. Even if the family, in the end, agrees with the physician, it may not be due to the medical decision, but because the family changed their minds from a religious or halachic point of view. And if the physicians decide to agree with the family, it is probably not because the family convinced them of any religious truth, but only because of the respect for religious views or a fear of ending up in court.

In the quest for reciprocity, we also consider the educational level of the family. Some families find it easier to talk, others do not. There is also a larger anxiety level when the patient is young. Both family and physician clearly feel that death is the enemy. It is upon these grounds that there is a willingness to communicate reciprocally. If the patient is older, there may be strong differences in how to treat the patient. Arguments will spill over different concepts of quality of life and sanctity of life and communication will bog down. Some families are hoping for a miracle, while physicians know that miracles almost never happen. Finally, physicians and families must realize

that their differences should be objectively presented and not involve any personal attacks involving the character of the disputants. In prolonged communication, this is quite difficult.

I suggest the following in the context of difficulties in finding reciprocity.

1) Air all disagreements. If we want to create an atmosphere of trust, put all disagreements on the table. Good communication allows and even encourages questions and differences of opinions. Sometimes it allows family members to ventilate their emotions and it is only this freedom to express their frustrations which they seek. It also helps *post facto*. Families will not say, "why didn't we express our true feelings to the medical staff before Ma died?"

2) In this situation, we have to remain calm, take it easy. It may take time. The patient may be looking "not bad" in the eyes of the family. So denial and hope becomes part of their thinking process. Problems occur when it takes too much time for any consensus to occur. In the meantime, we spend the physical and emotional resources of the staff, and probably the agony of the patient as well.

3) It is also possible that families go through the various stages, similar to what Kubler Ross describes. First, denial and shock, followed by anger at their sense of loss of power. There also may be anger at God and displaced anger towards the medical staff or family member who didn't prevent it from happening. Then there could be fear, not only fear of the future, but also fear in showing their own fright. There may also be fears of the patient leaving this earth with some unfinished business that the family cannot bring up in this situation.

4) We may also note ambivalent expressions of hope, despair, depression and bargaining all of which may occur in cycles. Guilt can be an important factor. The family may feel that it is a punishment for their sins of the past.[36] The family bargains with God, "We give Zedaka (charity), we will go to Shul (synagogue). Dear God, please help Mother etc."

5) Treating the family. We may ask, "So what if the family goes through various stages? Am I responsible to the family? I have enough on my hands treating the patient." The answer is that you don't have to treat the family. But helping the family helps the patient. Sometimes families are too involved with the situation, subjective in their thinking. You are able to help them support the patient. I have written at length about family traits, especially on protecting the patient and family guilt. Perhaps the patient has different ideas and is ready to accept the inevitable. Perhaps he/she may want to say something and wants you to listen. Families often come over to me, "Rabbi, why wasn't I there the moment he died? It's like I abandoned him." You can explain, "maybe it's in your imagination. First, he slipped into a coma, second, maybe he didn't want you to be there at the moment of death, that is why he was always sending you down to get a bite and have a break. Perhaps he felt that he just wanted to be left alone in his own world."[37] Finally, "what about all those years of a good marriage. Do you believe that they could disappear in one moment?"

6) We finally have to remember that we are there to generate agreement. Often, in our obstinency, we stop communicating with the family as if to say, "It's no use."

First, maybe there is room for agreement somewhere. Perhaps we could agree on an outsider who could come in and, once again, hear the issues. Perhaps agreement can be made on visitations. Communications must always continue. The cracks in family and physician inflexibility should be noted. Sometimes it just takes time until families realize what is happening and accept the advice of the medical team. Sometimes we invite second and third opinions or use the ethics committee or consultants until the families get the message.

What We Have Learned - A Conclusion

As this thesis comes to a finish, I begin to reflect on what I have initially tried to accomplish and how my thinking evolved as I was reading, studying, writing and being guided through my work during these past few years. No doubt, like all doctoral theses, it has been a learning experience, and as I conclude, I would like to share some of my thoughts on what I have learned.

As I began to write, I had some preconceived ideas of what I wanted to achieve. I saw the surging role of the family in physician-family communication, the weakened role of the physician in the hospital milieu and how they both felt as they communicated in the medically futile situation. I thought that this was a relatively unexplored area of research since the literature on doctor-family communication in general was sparse. As far as I know, it is still a relatively unexplored area, but like most writers, ethicists and researchers who emphasize the importance of communication in a medical setting, I

believed that my concerns surrounded concepts of futility, patient autonomy, informed consent and patient compliance. These writers did not emphasize the method or functional process of good communication. I, too, did not appreciate the necessity of placing any emphasis on how to communicate. This was a matter of common sense which we all claim to have. The main issue was that good communication is important for physician, patient and families and that we try to get the message across the table in a gentle manner. As the research progressed and I started to note the immense problems within the framework of medical futility in a hospital setting, I soon realized that the best way to approach the issue was to continue where others had left off. I would try to define good communication, examine the components and endeavour to fit them into a collaborative model.

As my research progressed, I tried to establish a suitable definition of futility which, in the end, I could not do. I looked at the different points of view of the stake-holders in the debate, the physician, family and government. Each argued convincingly for recognition and acceptance of their position. The government was asking for budgetary constraints and the search for a just medicare system which would accommodate all Canadians. The physicians argued for the dignity of their profession and that the medical decisions belong to their domaine. The families were looking for their rights of autonomy and an understanding that they have duties and obligations to their loved ones which they have lived with and loved for a lifetime and that any outside decisions were a matter which could not be imposed upon them. I also reviewed the various methods of solving the futility debate - without coming to a conclusion. I did,

however, conclude that a collaborative communicative approach is the most feasible. I am not certain that I have a definitive answer, for within communication I still realize that there are budgetary constraints and that the physicians and families do have legitimate interests and that all these forces are involved directly or indirectly within the communicative process.

I do know, however, that good communication is a powerful force which can bring people together. It is a most humane aspect of the practice of medicine. It can develop a bond between physician and family and the knowledge that each party is listening to what the other has to say. Bird recognizes the difficulties. He writes,

> Although there are no foreseeable ways to overcome moral diversity, having good conversations can at least initiate and establish communicative links among people with differing positions. Although we may not be able to achieve agreements regarding either our visions of moral good or the moral logic we use to justify our positions, through good conversations we can, from time to time, reach practical agreements about specific projects.[38]

This approach is the closest to the bottom-line in solving futility issues between families and physicians.

Earlier in Chapter VII, I listed the components of good conversation. I now examine the results of such conversation as explained by Bird and the effect it may have upon the players, including patient, family and physician. I believe that these are most important to state because, in the end, this is the crux of my thesis and this is what I have, hopefully, learned. First, good communication cultivates a sense of partnership. It makes us feel that we respect one another. It encourages us to voice our opinion. It gives us a sense that we are all struggling together in order to reach a solution.

Second, good conversations are educational. Bird gives an example of a neurosurgeon and parents of a suffering child with a serious nervous system disorder. The physician and family did not know what to do. At first the doctor discussed the case with the family from a bioethical standpoint which would consider the pain, risks, extraordinary means and viability of alternative approaches. Over time, however, they found it easier to talk of the decisions that had to be made. Bird writes,

> They found it easier both to express their feelings directly and to listen to what was being said to them. Even though from a textbook perspective, the decisions were becoming more difficult, the doctor and the families found it easier, having been educated by their developing conversations, to make the judgments they felt needed to be made.[39]

The major point is that as we learn, one from another, it allows us to use our imagination, to re-think, to re-consider and change our minds. If we view our conversations as educational, we come with an open mind and it allows us to express our opinions without losing face.

Thirdly, good conversations cultivate a sense of trust. In a hospital, as one may imagine, this is a major concern of patients and families. There are so many uncertainties. Patients and families are on the defensive - on guard - in their initial approach to the hospital team. But as we proceed with our conversations, encouraging each other to be vocal and attentive and adhere to mutual promises, we begin to extend our trust. Trust is developed through good, honest and clear conversations and reciprocally, trust encourages good converation. My collaborative model encourages this trustful relationship which is basic to respectful and forthright communication.

Fourthly, Bird points to a strenghtening of feelings of consciousness through good

communication. The basis of my struggle in the face of futility is that families and physicians, at first, may be polarized in their thinking. The family has a duty to a parent; the physician, a duty to his/her profession. When I grapple about how to act in these cases, I begin to sense a clearer picture of priorties. Bird is sharp.

> To the extent that the external debates represent partial reflections and manifestations of our own inner struggles, ensuing conversations often not only reach their own resolutions, but, importantly, good reciprocating conversations call for us to empathize at least in part with our conversational partners.[40]

From my experience, many families who initially have their own personal opinions, ease in their hard positions after listening and absorbing what the physicians have to say. This is mainly due to their personal conscience about what is right for them to do. Of course, it can work in a second manner wherein physicians absorb what families have to say, giving them the opportunity to explore and learn how to balance their claims.

Fifth, good conversations occasion gracious initiatives. The reality of good conversation in a hospital is that there are ups and downs. As I pointed out, there are feelings of ambivalence which are normal responses by patients and families, especially in the medically futile situation. It is almost normal for a family to think of second opinions and earlier in Chapter VII I encouraged the team to suggest the idea of the second opinion to the family. This may be extremely important to the family. There is a tendency to see families as intruders who really don't belong in the medical decision process. Bird also argues that fundamentally it is only normal that good conversations are often difficult to sustain. Someone gets offended, momentarily inattentive and newer

problems arise which challenge previous understandings. Bird writes,

> These are all instances of what we might describe as the force of social entrophy, or the devolution of our communicative exchanges to less open, less reciprocating, less reasonable, and less trusting forms. What gracious initiatives do is reverse these trends they serve to address and overcome the forces of social entrophy.[41]

Gracious initiatives can revive stalled communication. This can occur when one or two parties extend themselves to motivate the stalled negotiations by conceding certain points, ignoring offensive comments and, especially, by not making an attempt to have the last word. It gives us a chance to pick up a stalled conversation and give our derailed and frustrated conversations and feelings a second chance.

Finally, and most important, is the realization that good communication unfolds over a period of time. This, perhaps, is the biggest obstacle within the framework of a hospital where physicians and administration seek to find the quick solution, the fast answer to their problems. Once again, I turn to the adminstrative model whose purpose is to focus upon the illness and not the patient as a whole. What does all this mean? Simply that conversations center on the illness and how to get the patient released from hospital as soon as possible. Further, as I have noted from my interviews, patients are older and physicians are overwhelmed with numbers, pressured to see as many patients as possible. With the patient and family I saw that appointments were hard to get, physicians have closed their practices to newer patients and the patients can wait for months for tests and treatments. On the hospital ward, physicians are harrassed by families who stand in corridors and who only want "a word" with the physician. When patients are told to leave the hospital, it is often on the spur of the moment. Pressures

arise from patients in emergencies for emptying the bed on the ward. The whole situation is geared for brief conversation. It's almost as if families and patients, some who need time, are pressured into making quick decisions.

I am not trying to set blame. It is not easy for any of the parties. Conversations, especially in regard to end-of-life decisions, require a number of encounters and this takes time. The physicians are reluctant to engage in any lengthy conversations because of the pressures. Families may call this abandonment. People need time to reflect, reconsider and adjust positions. I have tried to address this in our series of recommendations towards the end of Chapter VII, but in the end, it is the greatest challenge.

Overall, my study was a psychosocial survey of a group of Jewish families who confronted and communicated with physicians in a medically futile situation. I learned how these families perceived terminal illness, end-of-life decisions and their expectations from the physicians in their tragic situation. I examined the family setting, their values and traits which could affect communication and the medical decision process.

I also researched the physicians, how they perceived end-of-life decisions and their view of how they communicated with the family. I examined the physicians' setting from which they operate including the community, the Jewish General Hospital, their education in medical ethics and the financial pressures placed upon them by the government and administration. I also interviewed some from the higher echalons in hospital adminstration to obtain their view of the futility debate and how the government is trying to cope with the overwhelming financial problems. I believe that all these

stake-holders and forces impinge upon family and physician communication, especially in this emotional and financially straining situation.

As I began my thesis, I developed certain hypotheses as noted from my experience. The physicians claimed that they communicated well with the families and that medical decisions should be left up to the medical profession. In cases of impasse with families who insist on their full autonomy and rights, the doctors would generally follow the family wishes rather than go to court. For the physician, medical ethics is not etched in stone. They use common sense. The families believe that physicians were poor communicators and that patients had to be protected from being advised of the whole truth. Families believed that they had to be involved in all medical decisions and that their wishes should prevail in the end when in dispute by the physicians. By and large the hypotheses proved to be correct from the standpoint of the physicians and families.

Just after one of my interviews with the physicians I was asked, "Rabbi, what do you intend to prove with your research? It seems to me it's all *heresay*, nothing substantial, just stories." I tried to explain that my research was from a qualitative approach, and that the narrative, the story of how physicians and families perceive communication within futile situations, is important for all involved to know. But like many exchanges, it was only after we went our separate ways that I thought of other things I should have mentioned. Perhaps, "While it may not have the validity you seek, it does reflect on the art of medicine. Afterall, Doc, we all agree that medicine is not an exact science but an art as well." I began to reflect on my readings of Veatch, May,

and Bleich who questioned the role of the physicians in the futile medical situation and wondered if there are not other disciplines which have to be considered, such as law, philosophy, theology, and the humanities.

But after all is said and done, what I have accomplished is only a beginning. Further, the fact that I am the hospital chaplain and that I am paid by the hospital, no doubt, has perhaps swayed some of the replies I received from physicians and families. Perhaps if some more neutral observers had done this research, the results might have been different.

I do believe, however, that I have introduced into our hospital a study which was concerned with our understanding of culturally different psychosocial approaches to illness, end-of-life situations and how families from different ethnic cultural groups may communicate. These are important issues since a very large proportion of our patient population includes people from different ethnic groups, cultural and religious backgrounds. Just how do the Chinese, the Blacks, the Hindus, Moslems, Buddhists, Greek Orthodox, and Canadian Aboriginals view illness and futile medical situations? How do doctors respond or communicate with patients and families of different ethnic and cultural backgrounds? Do the physicians know their value systems? Do I know their style in communicating? Do I know what each group will expect of the physician? I have attempted to examine the Jewish communities' response. Research could be made in regard to many other groups. Is there a specific Christian response? Are there differences between Catholics and Protestants? I have found within each group different social considerations such as the different socioeconomic backgrounds which might be

taken into consideration. I only hope that my study may lead to additional research in this most sensitive and important area which will probably affect all of us at the end of life.

Notes

1. I have described this model at length in Chapter II. With governmental focus on saving money, hospital management now stresses a rapid turnover in an increasing elderly patient population.

2. In the end, they may dutifully say it was God's will, but at the same time they will blame the doctor. This is difficult to understand.

3. David H. Smith and Lloyd S. Pettigrew, "Mutual Persuasion as a Model for Doctor-Patient Communication", *Theoretical Medicine* 7, no. 2 (1986): 127-147.

4. *Ibid.*, 132-133.

5. *Ibid.*, 133. The authors note that there is even a journal, titled *The Journal of Compliance and Health*, which exists to report on compliance research.

6. *Ibid.*, 133. This is very much different than our general understanding of informed consent which would fundamentally have physicians recognize and respect patient autonomy. The authors are only describing how informed consent has developed in practice.

7. Jay Katz. The Silent World of the Doctor and Patient (New York: The Free Press, 1984), 3-4.

8. *Ibid.*, 111.

9. *Ibid.*, 121.

10. See Thomas Tomlinson, "The Physician's Influence on Patients' Choices", *Theoretical Medicine* 7, no. 2 (1986): 105-123.

11. The general consensus for most physicians would agree with Schneiderman and Jecker who say that if it (the treatment) hasn't worked in the last 100 cases then it is futile. Thus, even 2% is problematic.

12. I suspect that many physicians may appropriately feel that these conversations should be spread over a period of time. Unfortunately, because the nature of a teaching hospital encourages a constant changing of staff and that the staff, in general, does not have the time for any protracted second or third conversations, the doctor, patient and family are left in a state of uncertainty.

13. Mary L. S. Vachon, Occupational Stress in the Care of the Critically Ill, The Dying and the Bereaved, Clark Institute of Psychiatry, Toronto, Ontario. (New York: Hemisphere Publishing Corporation, 1987), 51-73.

14. Sharon Freedman, "The Impact of Hospitalization on Aging Holocaust Survivors and Their Families: The Implications for Delivery of Service with this Population", in selected papers from Time to Heal: Caring for the Aged Holocaust Survivor (Baycrest Centre, Toronto, Ontario: May 1999), 167-181.

15. David J. Bleich, Bioethical Dilemmas: A Jewish Perspective (Hobokan, N.J.: KTAV Pubishing, 1998), 128-129.

16. Ruth Purtillo, Health Professional and Patient Interaction (Philadelphia: W.B. Saunders Co., 1990), 200.

17. See p. 340-341.

18. Paul A. Ramsey, "The Indignity of Death with Dignity", On Moral Medicine, eds. Stephen Lammer and Allan Verhey (Grand Rapids, Michigan: Evan B. Erdsman Publishing Co., 1987), 185-196.

19. Frederick B. Bird, The Muted Conscience: Moral Silence and the Practice of Ethics in Business (Westport, Connecticut: Quorum Books, 1996), 207.

20. *Ibid.*, 85-121.

21. *Ibid.*, 211.

22. *Ibid.*, 209.

23. I have not included the social worker because families will usually want to hear from those who are directly involved with the medical procedures and medications. The social worker can be present; however, the social work role would be separate from this type of family/medical team contact.

24. *Ibid.*, 208.

25. Charles L. M. Olweny, "Effective Communication with the Cancer Patient: The Use of Analogies - Suggested Approach", Communication with the Cancer Patient. Annals of the New York Academy of Sciences, New York, N.Y. (1997), 179-187.

26. F. Bird, 215.

27. *Ibid.*, 217.

28. This applies to the Canadian Medicare System. In the United States, it is a major issue.

29. F. Bird, 217.

30. *Ibid.*, 112. Taken from Sissela Bok, "Lying: Moral Choice in Public and Private Life" (New York: Vintage Press).

31. See Bird, pp. 111-133 for a fuller discussion on the philosophical aspects of lying.

32. *Ibid.*, 219.

33. Patrick J. Irvine, "The Attending at the Funeral", *New England Journal of Medicine* (June 27, 1985): 1704-1705.

34. F. Bird, 220.

35. *Ibid.*, 211-212.

36. A Jewish belief is that each person is responsible for his brother. Therefore, I do a mitzvah so that it will hopefully help my family. When I sin, it may affect them negatively. Thus, the idea of bargaining is associated with guilt.

37. As per William May's description of the patient who detaches himself from his past.

38. F. Bird, 224.

39. *Ibid.*, 229.

40. *Ibid.*, 234.

41. *Ibid.*, 234-235.

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RESUSCITATION AND OTHER CRITICAL INTERVENTIONS

The SMBD-Jewish General Hospital is dedicated to the following goals for its patients: reversing disease states, optimizing function, and providing comfort. These goals will be attempted within the limits of the Hospital's resources.

There are a limited number of life-threatening medical events that occur suddenly and at unpredictable times. These include cardio-pulmonary arrest, acute haemorrhage, acute sepsis and acute cardiac arrhythmias. Unless interventions are immediately instituted the patient will likely die. It is, therefore essential to have a policy for these interventions so that a decision can be made prior to the critical event. This policy has been prepared specifically to deal with critical interventions.

Patients are entitled to refuse medical interventions. In the absence of an explicit and specific refusal, though, for all patients, regardless of their critical intervention status, attempts to correct those events that are easily reversible will be made. Such events include cardiac tamponade, and tension pneumothorax. Similarly, simple means of relieving distress (e.g. applying the Heimlich manoeuvre to a patient with a respiratory obstruction) will be applied as well. It is important to note that a decision to withhold one or more critical interventions does **not** automatically imply that the patient shall only be receiving comfort or palliative measures.

The decision process on critical intervention must be consistent with the values of openness, honesty, and respect for all parties involved. The mechanisms described below are designed to ensure discussions amongst all appropriate persons in order that informed and responsible decisions may be reached, consistent with the following points:

- Decisions about critical interventions must be seen in the context of a rational overall treatment plan. These are explained in the attached *Guidelines for Ensuring Continuity of Care.*

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Continuity of Care

- It is preferable that consideration and/or discussion of critical interventions not be left for first consideration in the context of a present or pending emergency. Rather, it should be initiated at admission or as early as possible. Indeed, ideally, some of these discussions would in fact have been held prior to hospital admission: for example, in a physician office, in a long-term facility, or in a patient's residence. Such information, ideally, would be transmitted to the treating team and considered when determining a patient's critical intervention status.

  If this information has not been transmitted, the treating team should take reasonable steps to obtain it.

- All relevant members of the health care team should be included in the discussion, implementation and review of discussion on critical interventions. To help enure full participation, all members of the treating team should be apprised of upcoming discussions of patient's critical intervention status so that they might arrange to participate in the discussion or to provide input in other ways.

- The patient's responsible physician is the attending staff doctor who has admitted the patient and/or is currently in charge of the patient's care. In the absence of any clear alternative, this role is played by the CTU director.

Acute Active Care

- The patient's responsible physician must review the decision on critical interventions to ascertain that the basis for that decision remains valid as soon as any relevant change, physical or psychological, occurs. In the absence of such change, the responsible physician must review and document these decisions on a weekly basis. Unless this review finds the situation to have changed in relevant respects, the decision-making process outlined below need not be undertaken anew.

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Long-Term Care

- Most decisions on critical interventions regarding patients designated as long-term care are based upon clinical situations that are unlikely to change. Regular review of the critical intervention status of these patients, while desirable, is not mandatory. However, in the event of a significant change in the patient's clinical status, which may or may not require new interventions, a reassessment of the patient's critical intervention status is required, and must be documented.

As is true of other medical acts and decisions within a teaching hospital, residents act in decisions about critical interventions and in their implementation under the authority of responsible attending physicians. A resident may be involved in the discussions and aspects of the decision-making process, and may write critical intervention orders. A critical intervention order written by a resident must be countersigned by the patient's responsible attending physician as soon as possible, but in any event within seventy-two hours of the writing of the initial order.

- Accurate documentation must be assured for all the above (see attached Critical Intervention Record Sheet).

In this document, references to communication with "the patient" apply to the competent patient[1], or to the patient's legal substitute (as described below) if the patient is incompetent.

Sharing information about the patient with family members, while important, should not be confused with determining a treatment plan. A treatment plan can only be prepared with the participation of the competent patient (or, if incompetent with the legal substitute)[2]. Such sharing of information should only be done with the patient's agreement.

1 Competent patients are distinguished from incompetent patients by their ability to understand and meaningfully choose amongst, or refuse, alternative courses of treatment.

2 Hospital policy on decision-making for patients under curatorship and those without an identified and involved personal proxy decision-maker is currently under development, and will affect implementation of this policy in those cases. Questions in this connection should be addressed to the Chairpersons of the Ethics Committee.

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POLICY AND PROCEDURES

A. When there is no substantial reason to suspect that a patient may require critical interventions, it is unnecessary and inappropriate for the health care professional to initiate discussion with the patient on this topic, and no documentation is required. If, however, a patient asks about critical interventions, his or her concerns must be addressed and documented.

B. The hospital accepts that a patient has died when that patient has irreversibly lost all brain function, including brain stem function. When death has been determined in accordance with accepted clinical criteria, no critical interventions will implemented, with the exception of those performed to sustain organ viability on behalf of donation.

With the exception of a patient who is a candidate for organ harvesting, the family should be notified of the patient's death following verification of the occurrence of brain death and the removal of all apparatus. When a patient is a candidate for organ harvesting, the apparatus required to sustain organ viability should remain, and the family should be notified of the patient's death.

C. Resuscitation will not be undertaken in those instances where there is no chance of effecting sustained and functional reversal of the critical event. This decision will be made and documented by the attending physician and requires a documented second medical opinion.

Examples of interventions precluded on this basis include:

1. Cardiac resuscitation of patients with progressive unrelenting cardiac failure, unsuitable for heart transplantation, that has culminated in cardiac arrest.
2. Intubation of patients with progressive, massive malignant involvement of the lungs.
3. Transfusion of patients with massive and persistent internal bleeding that cannot be surgically controlled.

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It is clear that it is rare for a patient to satisfy these stringent criteria; in these rare cases, since medical judgement indicates that resuscitation cannot succeed by any substantial measure, it need not be attempted, initiated, or if initiated, continued. Although patients must be apprised of the therapeutic plan, they need not be informed of all measures that are to be withheld on grounds of futility.

D. In some instances, it is concluded by the attending physician that the burden of a critical intervention upon a patient would be so disproportionate to its benefit that it would be contrary to professional integrity to provide it. In reaching such a judgement, the physician must rely upon clear medical evidence to support his/her opinion, that is readily available in the medical literature and does not merely reflect his/her personal view. This should be followed by a required documented consultation with a specialist or subspecialist with appropriate expertise. That consultant's view must concur with the referring doctor's for this process to proceed. In that case, the attending physician (or his/her delegate) should explain the intended treatment plan to the patient. The patient should at that time be given the opportunity to seek a further medical opinion by a physician of his/her choice. The physician chosen must, however, have recognized expertise within the medical community that is relevant to his case, and his/her opinion must itself be based upon reliable and documentable medical information. If, at that point, the disagreement persists, there should then be a consultation with the Ethics Committee to ensure wide representation (see below Points to Note, #4).

E. In all other cases, critical interventions are to be instituted for every person in the hospital in need of them. In the following three instances, however, discussion regarding the use of critical interventions must occur:

1. Those competent patients who express the wish not to undergo any or all critical interventions.

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2. Those incompetent patients whose legal substitutes (or, if there is more than one, substitutes') decision is that the patient not receive any or all critical interventions.

3. Those instances where a successful critical intervention would result in, or prolong, a questionable quality of life.

   In all these instances, the attending physician or resident should always have at least one other person present during the discussion with the patient. Normally, the nurse involved with the situation should be among those present during the meeting. Involvement in the discussion should reflect the functional relationship between the patient and the health care providers

4. In difficult situations, it is essential that consultation be sought. Depending on the nature of the case, consultants should include the hospital's chaplains, clinical ethicist, Ethics Committee, Department of Psychiatry, psychologists, social workers and others.

POINTS TO NOTE

1. **Refusal by Competent Patient**

   In the case of refusal of critical interventions by a competent patient, it is the obligation of the health care team to elicit the patient's understanding of the consequences of his/her refusal. It is essential that clear, simple language be employed. Euphemisms (e.g. "No heroics") should not be used. If, in the view of the health care team, the patient's decision is unreasonable, it is their obligation to use reasonable efforts to persuade him/her to change that decision, but if the efforts fail, the patient's decision must be respected.

2. **Refusal on Behalf of the Incompetent Patient**

   In the case of the incompetent patient, it is the obligation of the health care team to determine the identity of the legal substitute, and to determine if there exists a written statement or other evidence declaring the patient's treatment preferences. Help in identifying the legal substitute is available through the office of the Director of

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Professional Services. The same obligations on the health care team apply to the discussion with the legal substitute as is the case with the competent patient.

If the health care team believes that the legal substitute's decision is contrary to the expressed wishes or the best interest of the patient, then the health care team must consult the Director of Professional Services.

3. **Questionable Quality of Life**

In those instances where a critical intervention would result in or prolong a questionable quality of life, — examples include intractable pain. anguish, and/or deeply impaired cognition — then discussion concerning critical interventions should be instituted with the patient. The final decision on quality of life rests with the patient (or, if incompetent, with the patient's legal substitute).

4. **Procedure for Ethics Committee in Cases of Burden-Benefit Disagreement**

In these cases, it is the attending physician's responsibility to contact the chair of the Ethics Committee or the clinical ethicist, who will convene and chair a meeting. The persons who will participate in this will be agreed upon at that time; they should include from within the Ethics Committee membership as broadly representative as possible. It is important to note that all members of the health care team who are involved with the patient should be informed of, and have the opportunity to attend the meeting. It is especially important that the patient's designated specialist attend the meeting, or failing that, supply to the meeting appropriate documentation of his/her view. It is up to the chairperson to determine whether or not it would be appropriate for the patient and/or family members(s) or friend(s) to attend this meeting. If the patient's family (etc.) Is not going to attend the meeting then the chairperson, or his/her representative, should speak with the patient and/or family member(s) to ascertain their perspective and understanding of the situation. It is of utmost importance that all opinions be heard. Documentation of the meeting should be the responsibility of the chairperson.

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Following a full discussion, the meeting proceeds to attempt to reach a final determination of the issue. This second part of the meeting will be held in the absence of any family member or representative. If this meeting finds a consensus regarding the attending physician's proposed treatment plan, the patient should be so notified. If the disagreement cannot be reconciled, a medical consultation from outside the hospital must be obtained. If, after receipt of the outside consultant's opinion, the committee does not find consensus in favour of the attending physician's proposed treatment plan, and the attending physician persists in the opinion that providing the treatment in question would be contrary to his/her integrity, then the responsibility for caring for the patient should be assigned to another physician by the Director of Professional Services.

No treatment may be curtailed, withheld or withdrawn prior to the final recommendation of the Ethics Committee and there has been a reasonable amount of time for communication and discussion between the health care team and the family.

The conclusion of this meeting does not conclude the hospital's involvement in these cases. Appropriate hospital resources must be made available to assist the patient and/or family in the grieving process. The patient and/or family will be informed that the hospital will make every attempt to transfer the patient if the patient so desires. If another facility has expressed its willingness to accept the patient for care within a reasonable time period, and the patient and/or the patient's family desires transfer, the hospital must facilitate the transfer, which will be accomplished at the family's expense.

5. **Surgery, Anaesthesia and Critical Intervention Status**

The interaction of surgery/anaesthesia on the one hand and the patient's critical intervention status on the other hand, should be carefully considered prior to proceeding with these measures. New discussions or consultations may be needed. Attention should be paid to providing clear and specific documentation regarding agreed-upon interventions.

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TRANSMISSION OF INFORMATION

All discussions and decisions regarding critical interventions must be recorded in the Critical Intervention Record Sheet (see attached). Related medical orders must be documented in Doctor's Orders and in other appropriate documentation such as the patient's Critical Pathways from Cardiac/Progress Notes.

IMPLEMENTATION AND MONITORING OF POLICY

Upon acceptance of this policy by the appropriate bodies, responsibility for educating the hospital community about it and monitoring it must be designated in consultation with the Ethics Committee. In addition, the policy will be forwarded for informational purposes to those long-term care facilities and convalescent homes with whom the hospital shares patients (including Maimonides Geriatric Hospital, the Jewish Rehabilitation Hospital, the Jewish Hospital of Hope, the Jewish Nursing Home and the Miriam Home).

APPROVED BY: The Ethics Committee and Board of Directors

Code of Ethics of the Canadian Medical Association

Approved by the CMA Board of Directors, October 15, 1996

Preface

The Canadian Medical Association accepts the responsibility for delineating the standard of ethical behaviour expected of Canadian physicians and has developed and approved this Code of Ethics as a guide for physicians.

The Code is an ethical document. Its sources are the traditional codes of medical ethics such as the Hippocratic Oath, as well as developments in human rights and recent bioethical discussion. Legislation and court decisions may also influence medical ethics. Physicians should be aware of the legal and regulatory requirements for medical practice in their jurisdiction. However, the Code may set out different standards of behaviour than does the law.

The Code has been prepared by physicians for physicians. It is based on the fundamental ethical principles of medicine, especially compassion, beneficence, non-maleficence, respect for persons and justice. It interprets these principles with respect to the responsibilities of physicians to individual patients, family and significant others, colleagues, other health professionals, and society.

The Code is not, and cannot be, exhaustive. Its statements are general in nature, to be interpreted and applied in particular situations. Specific ethical issues such as abortion, transplantation and euthanasia are not mentioned; they are treated in appropriate detail in CMA policy statements.

Physicians may experience conflict between different ethical principles, between ethical and legal or regulatory requirements, or between their own ethical convictions and the demands of patients, proxy decision makers, other health professionals, employers or other involved parties. Training in ethical analysis and decision making during undergraduate, postgraduate and continuing medical education is recommended for physicians to develop the knowledge, skills and attitudes needed to deal with these conflicts. Consultation with colleagues, licensing authorities, ethicists, ethics committees or others who have expertise in these matters is also recommended.

The Code applies to physicians, including residents, and medical students.

General Responsibilities

1. Consider first the well-being of the patient.

2. Treat all patients with respect; do not exploit them for personal advantage.

3. Provide for appropriate care for your patient, including physical comfort and spiritual and psychosocial support even when cure is no longer possible.

4. Practise the art and science of medicine competently and without impairment.

5. Engage in lifelong learning to maintain and improve your professional knowledge, skills and attitudes.

6. Recognize your limitations and the competence of others and when indicated, recommend that additional opinions and services be sought.

Responsibilities to the Patient

Initiating and Dissolving a Patient-Physician Relationship

7. In providing medical service, do not discriminate against any patient on such grounds as age, gender, marital status, medical condition, national or ethnic origin, physical or mental disability, political affiliation, race, religion, sexual

orientation, or socioeconomic status. This does not abrogate the physician's right to refuse to accept a patient for legitimate reasons.

8. Inform your patient when your personal morality would influence the recommendation or practice of any medical procedure that the patient needs or wants.

9. Provide whatever appropriate assistance you can to any person with an urgent need for medical care.

10. Having accepted professional responsibility for a patient, continue to provide services until they are no longer required or wanted; until another suitable physician has assumed responsibility for the patient; or until the patient has been given adequate notice that you intend to terminate the relationship.

11. Limit treatment of yourself or members of your immediate family to minor or emergency services and only when another physician is not readily available; there should be no fee for such treatment.

Communication, Decision Making and Consent

12. Provide your patients with the information they need to make informed decisions about their medical care, and answer their questions to the best of your ability.

13. Make every reasonable effort to communicate with your patients in such a way that information exchanged is understood.

14. Recommend only those diagnostic and therapeutic procedures that you consider to be beneficial to your patient or to others. If a procedure is recommended for the benefit of others, as for example in matters of public health, inform your patient of this fact and proceed only with explicit informed consent or where required by law.

15. Respect the right of a competent patient to accept or reject any medical care recommended.

16. Recognize the need to balance the developing competency of children and the role of families in medical decision-making.

17. Respect your patient's reasonable request for a second opinion from a physician of the patient's choice.

18. Ascertain wherever possible and recognize your patient's

wishes about the initiation, continuation or cessation of life-sustaining treatment.

19. Respect the intentions of an incompetent patient as they were expressed (e.g., through an advance directive or proxy designation) before the patient became incompetent.

20. When the intentions of an incompetent patient are unknown and when no appropriate proxy is available, render such treatment as you believe to be in accordance with the patient's values or, if these are unknown, the patient's best interests.

21. Be considerate of the patient's family and significant others and cooperate with them in the patient's interest.

Confidentiality

22. Respect the patient's right to confidentiality except when this right conflicts with your responsibility to the law, or when the maintenance of confidentiality would result in a significant risk of substantial harm to others or to the patient if the patient is incompetent; in such cases, take all reasonable steps to inform the patient that confidentiality will be breached.

23. When acting on behalf of a third party, take reasonable steps to ensure that the patient understands the nature and extent of your responsibility to the third party.

24. Upon a patient's request, provide the patient or a third party with a copy of his or her medical record, unless there is a compelling reason to believe that information contained in the record will result in substantial harm to the patient or others.

Clinical Research

25. Ensure that any research in which you participate is evaluated both scientifically and ethically, is approved by a responsible committee and is sufficiently planned and supervised that research subjects are unlikely to suffer disproportionate harm.

26. Inform the potential research subject, or proxy, about the purpose of the study, its source of funding, the nature and relative probability of harms and benefits, and the nature of your participation.

27. Before proceeding with the study, obtain the informed consent of the subject, or proxy, and advise prospective

subjects that they have the right to decline or withdraw from the study at any time, without prejudice to their ongoing care.

Professional Fees

28. In determining professional fees to patients, consider both the nature of the service provided and the ability of the patient to pay, and be prepared to discuss the fee with the patient.

Responsibilities to Society

29. Recognize that community, society and the environment are important factors in the health of individual patients.

30. Accept a share of the profession's responsibility to society in matters relating to public health, health education, environmental protection, legislation affecting the health or well-being of the community, and the need for testimony at judicial proceedings.

31. Recognize the responsibility of physicians to promote fair access to health care resources.

32. Use health care resources prudently.

33. Refuse to participate in or support practices that violate basic human rights.

34. Recognize a responsibility to give the generally held opinions of the profession when interpreting scientific knowledge to the public; when presenting an opinion that is contrary to the generally held opinion of the profession, so indicate.

Responsibilities to the Profession

35. Recognize that the self-regulation of the profession is a privilege and that each physician has a continuing responsibility to merit this privilege.

36. Teach and be taught.

37. Avoid impugning the reputation of colleagues for personal motives; however, report to the appropriate authority any unprofessional conduct by colleagues.

38. Be willing to participate in peer review of other physicians and to undergo review by your peers.

39. Enter into associations only if you can maintain your

professional integrity.

40. Avoid promoting, as a member of the medical profession, any service (except your own) or product for personal gain.

41. Do not keep secret from colleagues the diagnostic or therapeutic agents and procedures that you employ.

42. Collaborate with other physicians and health professionals in the care of patients and the functioning and improvement of health services.

Responsibilities to Oneself

43. Seek help from colleagues and appropriately qualified professionals for personal problems that adversely affect your service to patients, society or the profession.

of the Jewish General Hospital

Preamble

- The Jewish General Hospital is committed to the advancement of medicine.
- This mission is achieved by research and scholarly inquiry conducted in the context of outstanding patient care and social concern.

Academic Status

- The Jewish General Hospital is an academic hospital affiliated with McGill University.

Teaching

- The Jewish General Hospital will continue to develop and promote an environment for the education of medical students, residents, nurses, researchers and other health professionals.

Research

- The hospital is committed to research to advance the knowledge of the prevention, cause and treatment of disease and disability.

Patient Care

- The Jewish General Hospital will strive to provide the highest quality of patient care.
- The Jewish General Hospital will provide community, primary, secondary and tertiary care, however, its emphasis will be on the provision of tertiary care through the development of Centres of Excellence.

Humanization of Care

- The hospital is committed to providing humane care and attention in a unique and individual way.

Human Resources

- The Jewish General Hospital will encourage and support professional endeavours and educational programs so as to fulfill its commitment to the growth and development of its employees and affiliated staff.

Concern for the Community

- The hospital is a non-sectarian institution respecting the concerns of all religions, cultures and ethnic communities.
- The Jewish General Hospital will continue to maintain an environment which respects the religious beliefs of the Jewish faith.
- The Jewish General Hospital will continue to play a key role in the maintenance and strengthening of the Jewish community.
- The hospital will play an advocacy role as related to the needs of the community that it serves.

APPENDIX D: INTERPRETING TORAH LAW IN MEDICAL ETHICS

In the Orthodox Jewish faith, the general belief is that the Torah, which includes the Pentateuch, and Oral Law, as written in the Mishna, was God-given and therefore immutable within time and space. With the advances in technology and especially in medicine, we now have the obligation to interpret an ancient Holy Law as a modern Holy Law - a very difficult task. To do this, we look at the a) Sources of Principles in Jewish law, including those between man and God and between man and man, and b) the Halachic reasoning which is a combination of inductive and deductive knowledge. To do this is extremely complicated and subject to hermeneutic rules and a vast amount of interpretation. The expert in Halacha must be acquainted with the area of study and reasoning called the Sea of the Talmud, the Codes emanating from the Talmud and an ocean of Responsa dating from Talmudic times until the present. Interpreting a Holy Law naturally gives extreme respect to precedents which have been interpreted by the sages closest to the Talmudic era. Thus, in the case of Mr. E, the rabbi felt it was impudent for the physician to offer an interpretation of the Halacha.

From my experience, there are three models of interpretation which overlap. Some rabbis will stress the principles of man's relationship to God and will work primarily with sources and reasoning along very strict lines. I sense this in Rabbi J.D. Bleich's approach as I have shown throughout this thesis. A second approach will stress the principles concerning man's relationship to man and their sources which would be more lenient. This would be the approach of Rabbi M. Tendler whom I have also quoted throughout our thesis. This is not to say that both approaches are not considered objective. We all have biases and tendencies which

lead us to lean towards a certain reasoning which would make us comfortable. In such research, however, this should be spelled out from the beginning. A third group of rabbis try to balance both sets of principles and Halachic guidelines. In all cases, the Orthodox Halachist expert must make his decision through a process which includes a commitment to Orthodox theological beliefs and an accepted Halachic methodology which uses authoritative texts. It is my belief that he should also have extensive knowledge in medical ethics and experience in the medical arena dealing directly with physicians, patients and families.

Halakhic Guidelines for Physicians in Intensive Care Units*

Prof. Avraham Steinberg, M.D.

The following guidelines were formulated in consultation with Rabbi Shlomo Zalman Auerbach שליט"א and זצ"ל Rabbi Shemuel ha-Levi Wosner, who reviewed the original Hebrew and gave their approval.

A. The guidelines below apply to intensive care unit (ICU) patients only when all of the following conditions apply:

1. The patient was admitted to the ICU with the assumption that his life might be saved.

2. The patient received complete intensive care treatment for his medical condition, including ventilation, treatment of infection, blood pressure control, blood clot and hemorrhage prevention, blood transfusion, intravenous feeding, and constant monitoring of blood pressure, pulse, respiration, and oxygenation.

3. At least three of the patient's vital systems have unquestionably and irreversibly failed and all treating physicians—that is, all physicians in the ICU and all assisting specialists—have decided that all possibilities of saving his life have been exhausted and death from his illness or injury is imminent.

4. All of the above have been met, the physicians believe that the patient is suffering greatly, and it can be assumed that if there is no hope for recovery, the patient would not wish to continue suffering.

B. The guidelines below apply to ICU patients of all ages: adults, children, and infants.

C. The halakhic principle pertaining to such patients is based on the balance between the obligation to save life and the prohibition against actively shortening life on one hand, and not prolonging unnecessary suffering when there is no hope for recovery on the other.

D. Therefore:

1. One should avoid introducing any new treatment that will only prolong the suffering of such a patient.

2. One should cease performing diagnostic tests, such as blood tests to determine the patient's condition, since they only add to the patient's suffering and have no benefit whatsoever.

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3. There is no need to continue monitoring a patient in this condition—that is, to continue checking his blood pressure, pulse, and oxygen saturation (even if the automatic monitors were already connected to the patient)—or to alter treatment as a result of the data on the screen since such examinations and treatments have no benefit whatsoever for the suffering patient.

4. One should continue analgesic treatment in order to reduce the patient's pain and suffering as much as possible.

5. It is forbidden to do anything that will lead to the patient's immediate death. Even if there is only a suspicion that the action will lead to his death, it is forbidden.

   5a. It is therefore forbidden to disconnect the patient from a respirator if the physicians believe that there is a possibility that his breathing ability is entirely dependent on the machine, and it is forbidden to abruptly withhold medications such as dopamine, which regulates blood pressure, if the physicians believe that doing so will cause the patient's blood pressure to suddenly drop and, therefore, result in his immediate death.

6. One may alter or cease treatments when the physicians do not believe that doing so will cause the patient to immediately die—even though, as a result, he will die from his illness or injury within a number of hours—provided that the physicians believe that the patient is suffering, the changes in treatment are gradual and controlled, and the patient is monitored following the changes.

   6a. It is therefore permitted to lower the rate of the artificial respirator to the point where the patient is still breathing on his own; to lower the respirator's oxygen concentration to twenty percent, which is the oxygen concentration of of regular air normally breathed; to gradually lower dopamine dosage if no significant change is expected in the patient's blood pressure—and even if a change is seen in his blood pressure, as long as it will not lead to his immediate death; to cease intravenous feeding—that is, the concentrated nutrition the patient is fed through the vein—and to feed him orally through a feeding tube or even to feed him sugar and water solution intravenously; to discontinue medications given to prevent blood clots and hemorrhages, such as heparin and H2 blockers; and to discontinue insulin given to lower high blood sugar levels. All this is on strict condition that the patient is terminal and suffering greatly.

   6b. It is therefore permitted not to renew medications or treatments given periodically rather than continuously. For example, one need not restart dopamine or antibiotic treatment after the IV bag has been emptied. All this is on strict condition that the patient is terminal and suffering greatly.

E. These guidelines pertain only to patients as described above (A, B). For all other cases a halakhic authority should be consulted.